

EXPERIENCES AND PERCEPTIONS OF FATHERHOOD AMONG FATHERS WITH  
SONS WHO HAVE AUTISM SPECTRUM DISORDERS

A Dissertation  
by  
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## ABSTRACT

### EXPERIENCES AND PERCEPTIONS OF FATHERHOOD AMONG FATHERS WITH SONS WHO HAVE AUTISM SPECTRUM DISORDERS (May 2010)

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The purpose of this study was to expand on the research of Long (2005) and address the gap in the research literature related to the role of fathers of children with autism spectrum disorders, the intimate relationships fathers experience with their sons who are diagnosed with autism spectrum disorders, and changes in the fathers' perceptions of fatherhood.

A qualitative, phenomenological research approach was used for this study to explore the following questions: (a) What are the experiences among fathers of sons with autism spectrum disorders? and, (b) How do fathers' perceptions of fatherhood change through the experience of parenting a son with an autism spectrum disorder? Participants were selected

using the criteria of biological fathers who have sons with autism spectrum disorders, excluding Rett syndrome and childhood disintegrative disorder, and who were currently married to their sons' mothers. Six fathers of sons with autism spectrum disorders were interviewed regarding their sons' diagnoses, views on fatherhood, and changing experiences related to having a son with an autism spectrum disorder. Data collected from interview transcripts and field memos were analyzed and organized into themes. Six major themes emerged from the interview data: 1) concerns for their sons' future; 2) behavioral impacts of the son on family social life; 3) experiences with their own fathers; 4) involvement in their sons' education; 5) differences in parenting their sons versus typically developing siblings; and 6) changing views as fathers.

The six fathers who participated in this study have myriad experiences with their sons who have an autism spectrum disorder. Each father described positive relationships with their son. The positive relationships between the fathers and sons correlated to the positive perceptions and relationships each of the fathers shared with their own fathers. All fathers had concerns for their sons' futures and experienced the impact of negative behaviors associated with autism spectrum disorders on their family social life. Moreover, differences in concerns for the future and the impacts that their sons' behaviors had on family social life correlated to the differences in three separate age groups of the sons.

Differences were also present in how the fathers parented their sons with an autism spectrum disorder versus their typically developing children. Expectations of the other children in the family appeared to be higher with regard to behavior and social skills. All fathers were involved in some capacity with their sons' educations. This involvement varied from assisting with homework to fully participating in the educational decision-making

process. With regard to changing views on fatherhood, participants shared various responses. Changes included feelings of personal growth, development of patience, understanding of challenges, and growth in parental responsibility. This study offers several implications for school leaders and administrators and provides suggestions for further research.

## DEDICATION

This dissertation is dedicated to my son, John Paul.

Love, Dad

## ACKNOWLEDGEMENTS

I would like to express my love and gratitude to my wife, Jo-Nell, my family, and my friends for supporting me through this endeavor. I would also like to convey my recognition and gratitude to Dr. David A. Koppenhaver, Dissertation Chair, and Dissertation Committee Members, Dr. Roma Angel and Dr. Morgen Alwell. In addition, I would also like to provide recognition and gratitude to Dr. Linda O'Neal, former Dissertation Committee Member; to Dr. Alice Naylor, former Doctoral Program Director for Appalachian State University, who helped me get started on this process; and to Dr. Jim Killacky, present Doctoral Program Director, who has helped me to complete this process. I am also grateful to Dr. Timothy Markley, Superintendent of Catawba County Schools, for continuing to remind me to get this finished. Most of all, I want to thank and praise six wonderful fathers, who are heroes in my eyes, for their dedication and never-ending commitment to their children and families.

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## CHAPTER 1

### INTRODUCTION

Autism spectrum disorders are developmental disabilities characterized by varying impairments in three broad categories: (a) social development and social interaction; (b) communication and development of communication skills including verbal and non-verbal communication; and, (c) unusual behaviors involving routines, repetitions, and behavioral patterns (American Psychiatric Association, 2000). The most current diagnostic criteria from the *Diagnostic and Statistical Manual of Mental Disorders* for autism spectrum disorders include five specific disorders. These disorders are autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), Asperger's syndrome, Rett syndrome, and childhood disintegrative disorder (American Psychiatric Association, 2000; National Institute of Mental Health, 2008).

Over the past decade, an increase has been observed in the prevalence of autism spectrum disorders (Centers for Disease Control (CDC), 2007). The CDC survey based information on the assignment of a diagnosis of autism spectrum disorder from school records of 8-year-old children from 14 communities across the United States. The CDC estimated prevalence rates of children with autism spectrum disorders at 1 in 500 to 1 in 150 (National Institute of Mental Health, 2008).

The increasing prevalence of autism spectrum disorders, particularly in schools, has affected me as a school principal. In 2002, when I became an elementary school principal, our school district initiated a new special education program at my school. This program was

designed to serve children with autism spectrum disorders as well as other children who had communication disorders. This program was the third of its kind in our school district and was created because of increasing demands within the school district to serve a growing population of children with autism spectrum disorders. Of the eight students initially enrolled in the program, five were diagnosed with autism spectrum. All the students with autism spectrum disorders enrolled in the program were male, which is consistent with research showing a higher prevalence of autism in boys rather than girls (Baker, 2002; Bertrand et al., 2001; Dunlap & Bunton-Pierce, 1999; Fombonne, 1999; Lingam et al., 2003; Muhle, Trentacoste, & Rapin, 2004; Pinborough-Zimmerman et al., 2007; Volkmar et al., 2004; Yeargin-Allsopp et al., 2003).

As principal, I worked closely with parents of the children in this class to understand the issues related to educating and living with children with severe disabilities. I began to see in my interactions with parents that living with a child with a severe disability can be extremely challenging. The parents who seemed to have the greatest difficulties were those parents with children with autism spectrum disorders or the children who had high needs because of intense care or behavioral issues. During the first few years of the program, I worked mainly with the mothers of these children. In the rare instances that I met with fathers and mothers in Individualized Education Plan (IEP) meetings, I observed a range of emotions and behaviors from fathers. These emotions and behaviors included silence, crying, and anger. Once, I observed a father become so frustrated that he refused to participate in meetings and discussions related to his son. This father declined to be in the same room where the meeting occurred. Later, this father shared that he found it too painful to talk about his son's disability while in the meeting. In another IEP meeting, a father of a

child with autistic disorder informed the IEP team that the members had no idea what it was like to have a son with autism, and then he cried for the remainder of the meeting.

#### Statement of the Problem

My interest in fathers of children with autism spectrum disorders has evolved from my experiences in observing their emotional struggles as well as their relative absence from involvement in their children's education at the school level. Frequently, fathers have been regarded as the hidden parent in their children's schools and have been much less likely than mothers to be involved in their children's educations (Nord, 1998). Chesler and Parry (2001), in their research related to the experiences of fathers, noted that the actual voices of fathers or their own articulation of concerns and struggles are seldom known or heard.

A consistent focus in the research on parents of children with autism spectrum disorders involves mothers. In a preliminary review of the literature regarding fathers and autism spectrum disorders, little formal research was discovered regarding the specific experiences of fathers with a son with an autism spectrum disorder. Based on the limited knowledge and formal research that exists regarding fathers of sons with an autism spectrum disorder, it is important for educators and researchers to understand the emotional and psychological experiences of fathers with their sons with autism spectrum disorders.

#### Purpose and Description of the Study

The purpose of this study was to expand on the research of Long (2005) and address the gap in the research literature related to the role of fathers of children with autism spectrum disorders, the intimate relationships fathers experience with their sons diagnosed with autism spectrum disorders, and changes in their perceptions of fatherhood. At the time of this study, no research examining changes in the perceptions and beliefs about issues of

fatherhood in fathers who have sons with autism spectrum disorders had been discovered. A qualitative, phenomenological research approach was used to explore the following questions: (a) What are the experiences among fathers of sons with autism spectrum disorders? and, (b) How do fathers' perceptions of fatherhood change through the experience of parenting a son with an autism spectrum disorder? Participants were selected using the criteria of biological fathers who have sons with autism spectrum disorders, excluding Rett syndrome and childhood disintegrative disorder, and who were currently married to their sons' mothers. Six fathers with sons with autism spectrum disorders were interviewed regarding their sons' diagnoses, views on fatherhood, and changing experiences related to having a son with an autism spectrum disorder.

#### Significance of the Study

Observations of the emotional difficulties displayed by the parents I worked with were consistent with the types of reactions that parents often experience in having a child with a disability. Parent reactions to learning that a child has a disability often include feelings of fear, anger, loneliness, guilt, anxiety, and self-doubt (Featherstone, 1980; Huber, 1979). The fear parents have related to a child with a disability is the disruption of the anticipation about the natural order of life's events for their children. Parents who have a child with a severe disability face greater uncertainties about the future prospects of their child and feel as if they have been cheated from their own opportunities of parenting. Huber noted that all parents have an image of their children, as they want them to be. These images are often reflections of the parents' perceptions of them and expectations of their children's future achievements. Huber further noted that regardless of when parents learn that their child has a disability, at birth or later when performance differences are identified the

difference between parent expectations and the realities of seeing the child as different cause parents to experience feelings of loss and grief.

With specific regard to father-son relationships, Morman and Floyd (2002) have argued, “Without question, the relational dynamic experienced by men within the father-son dyad is a source of significant and long-lasting influence on a host of psychosocial and developmental issues in the lives of men” (p. 395). Floyd and Morman (2003) added, “The father-son dyad might be the most socially significant male-male relationship in the life course” (p. 599). Yablonsky (2000) stated, “The most important role a man can play in his lifetime is that of becoming a father,” that for most fathers, sons are “ego extensions” of themselves, and “a son’s successes and defeats are felt deeply by the father” (pp. 13-14). Morman and Floyd (2002) explained that fatherhood is more than biological. Instead, being both a father and a man are processes that are socially constructed and prescribed.

The most recent research concerning fathers’ experiences in rearing sons with autism was conducted by Long (2005). This research was limited in that only four fathers with sons with autism were involved. Using a phenomenological qualitative approach, Long explored how fathers of sons with autism make meaning of such an experience. Long concluded that the limited participation by fathers in her research may possibly reflect difficulties that fathers face in talking about their sons with autism, and that traditional types of support groups and activities designed for fathers may need new approaches to be more successful in recruiting them for participation and research. Long noted that the fathers in her study expressed a desire for knowledge about autism and treatment and social options/activities designed specifically for fathers and sons with autism. Due to the limitations in the research related to the experiences and perceptions of fathers and sons with autism spectrum

disorders, there is a need to further investigate the experiences and psychological aspects of fatherhood in men who have sons with autism spectrum disorders.

#### Definitions of Terms

For this study, the term father, referred to biological fathers who have sons with autism spectrum disorders excluding Rett syndrome and childhood disintegrative disorder and were currently married to their sons' mothers. The identification of themes for this study was defined as overlapping or repetitive clusters of statements that were organized into categories (codes) and sub categories (sub-codes) through the process of data analysis (Creswell, 2007).

#### Organization of the Study

This study was organized into five chapters. Chapter 1 has addressed the purpose and description of the study. Chapter 2 presents a review of the literature which underscores the gap in our knowledge addressed by this study and a conceptual framework that informed the articulation for collecting data. Chapter 3 introduces the methodological procedures employed in the study. Chapter 4 presents the findings of the study. Chapter 5 offers an analysis of the study's findings, the study's limitations, suggestions for further research, and implications for school leaders and administrators.

## CHAPTER 2

### REVIEW OF THE LITERATURE

#### Introduction

The purpose of this chapter is to provide a review of the literature related to parenting children with disabilities with particular attention given to fathers of sons with autism spectrum disorders. First, there is a review of the literature regarding autism spectrum disorders, a description of each disorder under the spectrum, and the prevalence of autism spectrum disorders. Then follows the literature related to parenting children with disabilities. This section of the literature is important as it addresses the contexts related to the reactions that parents have when discovering they have a child with a disability, stress associated with having a child with a disability, and an overview of the strategies of coping with children who have disabilities. Last, there is a review of the literature related to parenting children with autism spectrum disorders. This section provides insight into the lives of families with children with autism spectrum disorders and differentiates between mothers and fathers with specific focus on stress and coping. The review concludes with a specific focus on the formal research directed at fathers of sons with autism spectrum disorders and the articulation of a conceptual framework.

## Autism Spectrum Disorders: History, Characteristics, and Prevalence

### *History*

The word “autism” is derived from the Greek word “autos” which means “self.” In 1911, psychiatrist Eugen Bleuler first used this term in association with conditions of schizophrenia. While this term has existed for nearly a century, it was not until 1943 that Leo Kanner at Johns Hopkins University first identified autism as a distinct disorder and condition. In 1944, Hans Asperger, an Austrian pediatrician, published his doctoral thesis describing autism in case studies of four boys. Although independent in their research, both Kanner and Asperger believed that the observed conditions were biological disturbances present from birth (Frith, 2003).

The children with autism described by Kanner possessed the following characteristics: (a) extreme aloneness, (b) anxiously obsessive desire for the preservation of sameness, (c) excellent rote memory, (d) delayed echolalia, (e) over-sensitivity to stimuli, (f) limitations in the variety of their spontaneous activity, (g) good cognitive potentials; and (h) highly intelligent families (Happé, 1995). The first set of diagnostic criteria established by Kanner and Eisenberg (1956) identified extreme isolation and obsessions focused on sameness as the primary characteristics of autism (Frith, 2003; Happé, 1995; Longenecker, 2002).

Since Kanner’s original description of autism, modifications have occurred with definitions. Wing and Gould (1979) formulated the concept of a spectrum that showed associations between three core impairments. These impairments, known as Wing’s triad, are the basis for a diagnosis of autism today and include impairments of reciprocal social interaction, verbal and nonverbal communication, and imagination with a focus on repetitive

behaviors (Happé, 1995; Frith, 2003; Wing, 1997). Wing (1988) further elaborated autism as part of a spectrum of disorders that have a range of behaviors existing within a set of symptoms.

The creation of the autism spectrum acknowledges that autism ranges from severe to milder forms. Clinical and diagnostic descriptions of autism spectrum disorders are “characterized by qualitative abnormalities ... [that] are a pervasive feature of the individual’s functioning in all situations, although they may vary in degree” (ICD-10) (World Health Organization, p. 198). The most current diagnostic criteria from the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* for autism spectrum disorders include five specific disorders. These are autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), Asperger’s syndrome, Rett syndrome, and childhood disintegrative disorder (American Psychiatric Association, 2000; National Institute of Mental Health, 2008).

#### *Autistic Disorder*

Criteria for determining autistic disorder described in the *DSM-IV* suggest that individuals must exhibit at least six symptoms with a minimum of two symptoms falling under the category of impairment in social interaction, one impairment falling under communication, and one impairment falling under restricted behaviors, interests and activities (American Psychiatric Association, 2000). In addition to the aforementioned impairments, onset of delays or impairments must occur prior to the age of three, and the impairments must not be determined to better fit under the qualifications of Rett syndrome or childhood disintegrative disorder (American Psychiatric Association).

With regard to impairments involving social interactions, individuals diagnosed with autistic disorder may show impairments with multiple, non-verbal behaviors such as eye-to-eye gaze, facial expressions, body postures, or gestures that regulate social interactions; failures to develop peer relationships in accord with developmental levels; lack of shared enjoyment with others; and lack of social or emotional reciprocity. Impairments involving criteria related to impairments in communication may show individuals with a delay or lack of spoken language not accompanied by attempts to compensate through alternative modes; difficulty in conversation with others due to inadequate speech skills; stereotyped and repetitive use of language or idiosyncratic language; and lack of spontaneity in make-believe play or social imitative play. Individuals having a diagnosis of autistic disorder may show impairments such as stereotyped patterns of restricted behaviors, interests and activities or a preoccupation with stereotyped and restrictive patterns of interest; compulsive adherence to routines or rituals; stereotyped and repetitive motor mannerisms; and persistent preoccupation with parts of objects (American Psychiatric Association, 2000; Volkmar & Klin, 2005; Witwer & Lecavalier, 2008).

### *Asperger's Syndrome*

Asperger's syndrome, also referred to as Asperger's disorder, is a developmental disability consistent with the same qualitative impairments in social interaction combined with a restricted, stereotyped, and restrictive repertoire of interests and activities as found in autistic disorder. A defining difference in diagnostic criteria for Asperger's syndrome is the preservation of language development and cognitive abilities, whereas autistic disorder recognizes impairments in all three domains prior to three years of age. Due to the preservation of language development and cognitive abilities, the average age for diagnosis

of Asperger's syndrome is age 11 (Schnur, 2005). Individuals diagnosed with Asperger's syndrome do not have general delays related to language or cognitive development (Barnhill, 2001; Klin, McPartland, & Volkmar, 2005; Volkmar & Klin, 2005; Witwer & Lecavalier, 2008).

Asperger's syndrome, unlike autistic disorder, was not recognized by the American Psychiatric Association as part of the autism spectrum until 1994 and continues to be both controversial and confusing regarding its inclusion in the autism spectrum (Barnhill, 2001; Volkmar & Klin, 2005). Central to this controversy is considerable debate over whether Asperger's syndrome truly is separate from autistic disorder or whether it is actually a form of high functioning autistic disorder (Klin et al., 2005).

#### *Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS)*

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) is the diagnostic term describing a severe deficit in social learning and reciprocity in verbal or non-verbal communication skills. Individuals diagnosed with PDD-NOS have social deficits that arise in the first few years of age and are similar to other disorders on the autism spectrum; however, level of severity does not meet the restrictive criteria for disorders such as autistic disorder, Rett syndrome, or Childhood Disintegrative Disorder (Witwer & Lecavalier, 2008; Towbin, 2005; American Psychiatric Association, 2000). Towbin (2005) noted that a diagnosis of PDD-NOS may take on multiple meanings and that diagnosticians may apply up to four different definitions for different circumstances including: (a) a default diagnosis when information is unavailable or inadequate, or as a last resort, until the clinician can obtain a clearer understanding; (b) when impairments in communication or restricted behaviors are mild or possibly absent and the impairment in one of the domains (social,

communication, restricted behaviors) is too mild to allow an assignment of another diagnosis; (c) when there is a late age of onset of symptoms related to autism; and (d) for other conditions with other symptoms that are not part of the autism spectrum such as disordered understanding of affect, affective modulation, and patterns of attachment.

### *Rett Syndrome*

Unlike the other disorders existing under the autism spectrum, Rett syndrome has a higher prevalence in females (Kozinetz et al., 1993; Van Acker, Loncola, & Van Acker, 2005). Since the first descriptions of the syndrome by Andreas Rett in the mid-1960s and the initial diagnostic criteria developed in the mid-1980s, criteria for Rett syndrome have undergone several revisions. Criteria for this disorder as described by the most recent *DSM-IV* included individuals having normal prenatal and perinatal development and normal psychomotor development through the first five months of birth. Onset of the following symptoms then begins following the period of normal development: (a) deceleration of head growth between 5 and 48 months; (b) loss of purposeful hand skills between 5 and 30 months with stereotyped hand movements such as hand-wringing and hand-washing; (c) loss of social engagement; (d) poor coordination in gait and trunk movements; and (e) impairment in expressive and receptive language development with severe psychomotor retardation. Other associated features and disorders that often accompany Rett syndrome include severe or profound intellectual disabilities, seizure disorders, and non-specific abnormalities with brain imaging (American Psychiatric Association, 2000; Van Acker, et al., 2005).

With regard to physiological and pathological aspects of Rett syndrome, a high number of cases are linked to a mutation of the MECP2 gene, functioning as a regulator of the X chromosome (Armstrong, 2002; Glaze, 2005; Van Acker et al., 2005). Due to reported

variations in mutations of the MECP2 gene ranging from 35% to 87% tested, specificity in diagnostic markers for Rett syndrome continues to have some variation in the ability to provide a specific diagnosis for the disorder and may often have a differential diagnosis (Van Acker et al.). Depending on the stage of development of the individual having Rett syndrome and the clinical characteristics associated with it, Rett syndrome clinicians may provide misdiagnoses of such conditions as Prader-Willi syndrome, cerebral palsy, autism, encephalitis, phenylketonuria, Angelman syndrome, and unknown degenerative disorder (Van Acker et al.).

#### *Childhood Disintegrative Disorder (CDD)*

Childhood Disintegrative Disorder (CDD) has a long history as a disorder originating in the beginning of the twentieth century. A typical diagnosis of CDD occurs when a child has apparent normal development for at least two years and then has marked regression in abilities related to language, gesture, social relationships, and play. An important difference between CDD and autism is the course of early development and age of onset. Development prior to onset should be reasonably normal with children usually having the ability to speak in sentences by age two years. Onset of CDD occurs in many different patterns from gradual regression in weeks to months to that of an abrupt onset that occurs in a period of days to weeks. While there exists a clearly defined set of diagnostic criteria for CDD, a great deal of controversy exists regarding diagnosis due to the exactness of a regressive timeframe as well as ambiguities associated with other health problems that children may be facing (Malhotra & Gupta, 1999; Mouridsen, 2003; Volkmar, Koenig, & State, 2005).

### *Prevalence*

In recent years, mainstream media has referred to autism spectrum disorder as a silent epidemic affecting many children and families. Once thought to be rare, with reported rates of three to five cases per 10,000, autism and autism spectrum disorders have been estimated to have increased more than 1,100 percent from year to year in the early 1990's after students with autism were served under the Individuals with Disabilities Education Act (IDEA) (Yell & Katsiyannis, 2003). With these dramatic increases, the number of children with autism spectrum disorders served in schools within the United States continues to grow. In 1992, schools served approximately 5,000 students with a diagnosis of some type of autism spectrum disorder. By 2001, the number of children being served had increased to approximately 94,000 (U.S. Department of Education, 2002).

The dramatic rise in the prevalence of autism spectrum disorders is controversial among scientists and researchers. Since the 1960's, researchers have published numerous surveys and studies providing estimates of the frequency of occurrence in defined populations (Blaxill, 2004; Fombonne, 2003; Fombonne, 2005a; Fombonne, 2005b). Part of the controversy arises because of the broadening of the autism spectrum and expansions of the diagnostic criteria associated with each of the disorders. Other areas of controversy relate to the confusion that exists between the meanings of prevalence and incidence. The majority of studies focus on prevalence rates (total number of cases at any specific period), while few research studies focus on incidence (number of new cases within a specific period) (Volkmar, Lord, Bailey, Schultz, & Klin, 2004).

In a study examining the prevalence of autism spectrum disorders in metropolitan Atlanta, Georgia in 1996, 987 children between the ages of 3 to 10 years were screened for

autistic disorder, Asperger's syndrome, or PDD-NOS. The results of this screening revealed the prevalence for autistic disorders was 3.4 cases per 1,000, or higher than studies previously conducted in the 1980's and early 1990's (Yeargin-Allsopp et al., 2003). One of the most thorough studies conducted in attempting to determine prevalence using current diagnostic and epidemiological methods in a specifically defined community occurred in Brick Township, New Jersey. This study determined that the prevalence of all autism spectrum disorders combined was 6.7 cases per 1,000 children (Bertrand, Mars, Boyle, Bove, Yeargin-Allsopp, & Decoufle, 2001). Following the Brick Township study in 2002, data were collected from 14 surveillance network sites across the United States to determine the prevalence of autism spectrum disorders among children aged eight years old. Prevalence among 407,578 eight-year-old children from 14 areas ranged from 3.3 cases per 1,000 to 10.6 cases per 1,000 with an overall average of 6.6 cases per 1,000 or one of every 152 children across all the sites. Conclusions from this study have influenced public health reactions to autism spectrum disorders and provided some of the most complete information related to prevalence. Data from this study have given rise to autism spectrum disorders as a public health concern with estimates of one of every 150 children being affected and the need to improve areas of early identification (Morbidity and Mortality Weekly Report, 2002).

In a review of 37 epidemiological studies of autism and related disorders, excluding Rett syndrome, Fombonne (2005a) summarized conservative prevalence estimates for autistic disorder as 13 cases per 10,000; PDD-NOS as 21 cases per 10,000; Asperger's syndrome as 2.6 cases per 10,000; and CDD as two cases per 100,000 with survey prevalence estimates for all cases of autism spectrum disorders as six cases per 10,000. Fombonne noted

that an increase in prevalence rates most likely represents changes in diagnostic concepts and criteria, identification, and awareness among the public and professionals.

### Parents of Children with Disabilities

The literature on the effects of having a child with a disability spans nearly 100 years, with the majority of research focusing on the attitudinal effects on parents having a child with a disability. These effects commonly include feelings of guilt, denial, anger, and grief, or behavior effects, such as role disruptions, marital issues, and social withdrawal. Since the 1960's a great deal of the literature related to parenting children with disabilities has pertained to parental adjustment, with more recent research focusing on stress associated with family coping and adapting (Ferguson, 2002). This section examines general parent reactions to having a child with a disability and the literature related to stress and coping in having a child with a disability.

#### *Parent Reactions to Having a Child with a Disability*

Having a child with a disability can be a very difficult and intense emotional experience for parents and families (Burden, 1991; Glidden & Bush, 1990; Marvin & Pianta, 1996; Shonkoff & Others, 1992; Whelan & Walker, 2009). Ellis (1989) noted that when parents receive their child's diagnosis, this is usually the beginning of a family crisis due to the family being affected in several areas. Areas affected range from the need to provide immediate care; need to deal with increased levels of stress; need to deal with labels related to their child's diagnosis; difficulty in working through feelings of isolation, grief, anger, guilt, helplessness; and the impact on personal and family values and expectations.

Huber (1979) in his work on group counseling with parents noted that all parents have a particular image of how they would like their children to be and that these images are

reflections of themselves as parents and significant others who exist in the lives of the family. Along with these images are expectations of achievement, hopes for their children, and attributes of the perfect child. Huber added that regardless of when parents discover their child's disability, either at birth or when differences become apparent at a later age, the discrepancy between expectation and reality often causes parents to experience feelings of loss or grief; often following the same stages of loss outlined by Kubler-Ross (1969): denial, anger, bargaining, depression, and then acceptance.

Other researchers have provided a variety of models describing the ways in which parents and families react to having a child with a disability. Solnit and Stark (1961) noted that parents experienced grief through the loss of their idealized perfect child that involved three stages including numbness, disappointment, and re-experience. Olshansky (1962) identified the concept of chronic sorrow dealing with the experiences of parenting a child with a disability noting that parental grief is a continuous process that may exist for a lifetime with periodic resurgence of the parents' grief. Drotar, Baskiewicz, Irvin, Kennell, and Klaus (1975) conducted research on parental adaptation to a wide range of congenital abnormalities. In this research, Drotar et al. identified shock to be parents' initial response to a child's abnormality. Following their initial shock, parents continue to progress to the second stage of denial, then to a stage of sadness, anger, and anxiety; with a fourth stage occurring in adaptation; and a final stage ending in reorganization. In a review of grief processes of parents of children with disabilities, Ellis (1989) noted that most grief models focus on the more traumatic and overwhelming loss event and are not inclusive of how individuals experience growth. Ellis further added that Schneider (1983) created a model of grief different from other previously mentioned models for specific populations such as those of

parents of children with a disability. This model included six stages: (a) initial awareness, (b) awareness of loss, (c) strategies to overcome loss, (d) completions, (e) resolution and reformulations, and (f) transcending loss.

In explaining her own experiences of having a child with a disability as well as the experiences of other parents, Featherstone (1980) noted that the process of living with a child having a disability involves fear, anger, loneliness, guilt, self-doubt, and acceptance:

In telling the story of a child's disability, parents often begin with fear. Fear often arises long before their son or daughter earns any sort of official label, before the school or the doctor identifies an important difference. Over the years, fears change—in content, in quality, in intensity. Time does not usually banish them altogether, because the family of a disabled child must live with a special degree of uncertainty. Parents agonize about the limitations that the handicap will impose and about the world's response to difference. They worry about their child's future, about themselves, and about their other children. Brothers and sisters wonder anxiously about the place of the handicap in their own lives and about their future responsibilities. (p. 13)

The specific fears that parents face at the onset of identification of their child's disability often relate to thoughts about quality of life, independence, social acceptance, and general difficulties in life's course. With parents and families of more severely disabled children, when dependence seems inevitable, parents may experience fears and emotions related to institutionalization (Featherstone). Parents may face fears for their children and fears for themselves and their own life course. For many parents, the introduction of a child with a

disability changes the preconceived natural order by extending a child's dependence beyond what parents expect to provide with regard to vitality and health.

*Stress and Coping Related to Having a Child with a Disability*

A large body of literature documents the impact of stress related to having a child with a disability and the strategies that parents use for coping with such disabilities. Parents of children with disabilities often have higher levels of stress than families that do not have children with disabilities (Baker, Blacher, & Olsson, 2005; Baker et al., 2003; Baker-Ericzén, Brookman-Fraze, & Stahmer, 2005; Baxter, Cummins, & Yiolitis, 2000; Britner, Morog, Pianta, & Marvin, 2003; Crnic, Friedrich, & Greenberg, 1983; Dyson, 1997; Dyson, 1993; Dyson, 1991; Dyson & Fewell, 1986; Oelofsen & Richardson, 2006; Wilton & Renaut, 1986). A considerable amount of research exists comparing mothers and fathers to one another regarding the amount of stress that each parent experiences in having a child with a disability in the family. Research related to parental stress comparing mothers and fathers of children with disabilities has produced inconsistent results. Some studies have found that mothers experience greater levels of stress, anxiety, and emotional issues than fathers (Beckman, 1991; Davis & Carter, 2008; Hastings, 2003; Krauss, 1993; Saloviita, Itälinna, & Leinonen, 2003; Shin et al., 2006). Other research shows little difference in the amount or type of stress related to parent gender (Baker et al., 2003; Dyson, 1997; Esdaile & Greenwood, 2003; Housey, Best, & Blacher, 1992; Keller & Honig, 2004; McCarthy, Cuskelly, van Kraayenoord, & Cohen, 2006).

Coping strategies used by parents having a child with a disability can take on many forms such as seeking information, using professionals, attending counseling and therapy, communicating with professional and other parents, joining social support groups, and

reliance on religion. Research conducted by Pain (1999) and Taanila, Syrjälä, Kokkonen, and Järvelin (2002) noted that access to information by parents regarding their child's disabilities assisted the process of adjusting emotionally to their child's disabilities, enabled parents to access services and benefits, and improved their understanding of their child's behaviors or situation. Quite often, seeking information or gaining access to information occurred within some form of social support group or through other professional service providers. In recent years, many parents have been able to turn to the internet as a source of information assisting with coping and social support (Blacher & Baker, 2002; Blackburn & Read, 2005; Louie, 1996; Nolan, Camfield, & Camfield, 2008; Zaidman-Zait & Jamieson, 2007). In addition to information, the internet also contains electronic social support groups, chat rooms, and bulletin boards for enabling communication between parents with similar interests, concerns, and needs (Zaidman-Zaitand & Jamieson).

Social support for families of children with disabilities often takes on multiple forms at different levels. Schilling, Gilchrist, and Schinke (1984) identified three levels of social support for parents of children with disabilities. The first level includes nuclear family members, close friends, and close relatives. The second level includes neighbors, relatives that are more distant, friends, professionals, and service providers. The third level may include some form of social institution such as an association or organization serving families of disabilities. Several studies have identified various forms of social support (e.g. family support groups, professional service providers, parent to parent support) as effective in helping parents and family members cope with having a child with a disability (Adesida & Foreman, 1999; Cho, Singer, & Brenner, 2000; Gammon & Rose, 1991; Kerr & McIntosh, 2000; Kirkham, Schilling, Norelius, & Schinke, 1986; Kwai-sang Yau & Cecilia, 1999;

Leyser, Heinze, & Kapperman, 1996; Morison, Bromfield, & Cameron, 2003; Singer & Others, 1989; Solomon, Pistrang & Barker, 2001; Taanila et al, 2002).

A major area of parent support centers on counseling and therapy. Coping may occur through social support groups, professional service providers, and therapy sessions. Huber (1979) noted that parents participating in support group sessions become more aware of what is happening in their lives through the feedback of other parents and that groups often have a therapeutic effect. Huber added that as group members take advantage of the similarities of problems confronting them, they create interdependence and contribute new ways of coping to each other. Likewise, Shechtman and Gilat (2005) noted that in groups, parents often realize that they are not alone, gain knowledge about the disabilities of their children, and learn new coping strategies.

Coping through social support groups and the use of professional service providers often begins for parents using early intervention services that are available to parents and their children with disabilities. Under the Individuals with Disabilities Education Act (IDEA 2004), parents are provided the opportunity to have their children evaluated to see if they are eligible for early intervention and special education services. Parents having children younger than age three years can receive early intervention services that can include family support and child development support. Parents having children aged three to five years are eligible to receive services including special education and related services such as physical therapy and speech therapy.

Gilliland, James and Bowman (as cited in Ziolk, 1991) created a model of eclectic counseling that was applicable for use in counseling families of children with disabilities. This model of counseling involved a flexible and fluid process with the goal of cycling back

to the beginning stage. The stages in this model included: (a) building a trusting relationship; (b) verbalization of the emotional and factual aspects of the problem; (c) identification and evaluation of alternatives and commitment to a plan of action; and (d) summarization of progress and evaluation of the level of goal attainment with attention to other changes in strengths, needs, and pertinent available resources.

Coping for parents and families having a child with a disability also occurs through individuals relying on religion and personal faith. Research related to coping through religion and faith has often indicated that parents have a positive view of their child's disability or that their spiritual beliefs and faith assisted them in accepting and dealing with having a child with a disability (Dollahite, Marks, & Olson, 1997; Haworth & Hill, 1996; Leyser, 1994; Pitchlyn, Smith-Myles, & Cook, 2007; Tarakeshwar & Pargament, 2001; Weisner & Others, 1991). Tarakeshwar and Pargament noted that few studies have examined the relationship of religious coping to having children with disabilities and that most of the studies focused on religion and coping have focused on the positives of religion but neglected to study negative aspects.

#### Parents of Children with Autism Spectrum Disorders

##### *Stress and Coping*

Neely-Barnes and Dia (2008) noted that behavior problems and care needs related to a child's diagnosis were central to negative impacts upon the family. Parents of children with an autism spectrum disorder reported greater amounts of stress and depression than parents of typically developing children or children with other types of disabilities (Baker-Ericzén et al. 2005; Bristol & Schopler, 1984; Dumas, Wolf, Fisman, & Culligan, 1991; Fisman, Wolf, & Noh, 1989; Gray, 1994; Marcus, Kunce, & Schopler, 2005; Schieve, Blumberg, Rice,

Visser, & Boyle, 2007). Research studies conducted in recent years identified children's behavioral difficulties as a key component related to increased stress in parents of children with an autism spectrum disorders (Brobst, Clopton, & Hendrick, 2009; Bromley, Hare, Davison, & Emerson, 2004; Davis & Carter, 2008; Herring et al., 2006; Kasari, & Sigman, 1997; Lecavalier, Leone, & Wiltz, 2006; Szatmari, & Archer, 1994). Marcus et al. identified multiple stressors associated with the difficulties of coping with having a child with an autism spectrum disorder. These stressors often included: (a) family uncertainty of diagnosis; (b) complexity, and the length of time often associated with receiving a clear and accurate diagnosis; (c) difficulties with the course of child development; (d) confusion by parents related to their child's developmental patterns; (e) child deficits in social communication affecting family emotional relationships; (f) false expectations for parents due to normal physical appearance of the child; (g) disruptive or embarrassing public behaviors by the child; (h) parental coping with the child's autism as well as similar behaviors in other family members; (i) conflicts of the parents with professionals involving varying perspectives; and (j) false hopes in parents related to treatment.

Gray (1994) examined coping and stress, particularly involving family social experiences. In this research, Gray explored the most difficult problems parents of children with autism experience. Among the problems most often identified were poor language skills, inappropriate behaviors, embarrassing behaviors in public, violence, aggression, inappropriate sexual behaviors, obsessions with food, and toileting.

Parents of children with autism spectrum disorders may use a variety of strategies to cope with their child's disability. These strategies may involve support from family and friends, social support groups, early intervention programs, use of professionals, counseling

and therapy, and religion. Altieri and Kluge (2009), using a family systems approach, the relationships among the familial variables of cohesion, adaptability, and social support, noted that families of children with autism spectrum disorders who were connected to families and friends were more likely to engage in positive coping and effectively deal with stresses. Altieri and Kluge also noted, however, that there was less social support reported by fathers than mothers with regard to the support of friends. Some of the fathers felt that they lost friends because the friends did not comprehend the struggles associated with raising a child with autism, while others felt they lost friends due to having inadequate time to spend with them.

Luther, Canham, and Cureton (2005) conducted research using a descriptive survey design that examined coping and social support for parents of children with autism. In this research, the authors noted that both formal and informal social supports were important in helping parents as a coping strategy, and responses from participants were consistently high for social support from close friends and family members. In addition to social support from family and friends, the authors explained that at least half of the parents indicated they had attended or were interested in attending support groups relating to autism. Participants in this research recognized that some form of a support group benefited them by providing a place to discuss difficulties, to share coping strategies and accomplishments, and to meet other parents with similar situations.

In an examination of how parents with children who have autism cope over time, Gray (2006) observed that coping strategies changed over time. Initially fewer parents relied on service providers and family support while later more parents coped through their religious faith and emotion-focused strategies. Gray defined emotion-focused strategies as

coping that distracts the attention of the individual affected by a stressful situation (e.g., expressing feelings or praying). Gray hypothesized that parents of younger children with autism may rely more on problem-focused coping strategies (e.g. reliance on service providers, family support, social withdrawal, and individualism) as they begin parenting and move to more emotion-focused strategies overtime.

Rasmussen (2000) noted that parental reactions to having a child diagnosed with autism could be difficult. In examining parental reactions, Rasmussen identified difficulties associated with fear of the unknown related to autism, fear of low expectations from others, fear of financial demands, fear related to safety, and fear associated with constant care and attention. While parents experienced myriad emotions, both before and after learning that their child had autism, Rasmussen identified the most common feelings shared by participants to be guilt, blame, depression, fear, uncertainty, anger, frustration, distrust, love, hope, happiness, and acceptance. In learning to cope with their child's autism, Rasmussen noted that resources such as spousal support and using support groups were connected directly to feelings of acceptance. Similarly, Williams and Wright (2004) noted:

When a child is diagnosed with [autism], parents experience not only feelings of sadness and loss, but also a range of fears for the future, which replace the hopes and expectations that they may have had. These are difficult processes of adjustment. Families may have to realign their aspirations for their child, and keep the future in mind as their child develops. ( p. 35)

Others sources of stress may be associated with the difficulties that parents face in separating their child with autism from the home environment and acclimating them into other situations. Lee, Harrington, Louie, and Newschaffer (2008) concluded that families of

children with autism reported greater problems with childcare issues, less participation in activities, and less involvement in community services.

Extending research conducted eight years earlier Gray (2002) noted that over time parents of children with autism reported improved relationships with families. In a follow-up study, Gray found that difficulties associated with their children's communication were less frequently cited as a major coping problem for parents. Gray noted that this change might have been attributed to improvements in abilities or parental improvements in communicating with their children.

Gray (2002) observed two problem areas that continued to occur with parents over time. Gray noted that the anxiety levels related to their child's future had significantly increased as many of the participants' children had failed to attain a full range of living skills originally envisioned. Additionally, parents continued to experience issues with socializing and social rejection by others. Mothers were more likely to experience this than fathers were. Gray, however, noted that the impact of stigmatization might have declined over time, citing reasons that socialization issues mattered less because their children had improved with public behaviors, and as parents, they had less sensitivity to the reactions of others. Two conclusions emerged from Gray's research. The first was that most of the families in his longitudinal study had experienced improvement and favorable outcomes with their children with autism. Second, Gray noted that a variety of factors such as improved manageability of their children, accessibility to a variety of services, and increased coping skills, continued to help parents be successful over time.

Tarakeshwar and Pargament (2001) conducted research to assess the use of religious coping methods among parents of children with autism and examine their association with

psychological adjustment, stress-related growth, and religious outcome, defined as perceived changes in closeness to God, closeness to church, and spiritual growth. Study results indicated that greater use of positive religious coping methods was associated with greater stress relief and religious outcome, and religion appeared to be especially helpful to these parents in offering meaning related to their child's disability. Tarakeshwar and Pargament noted that participants consistently reported they looked to their church for support in meeting the demands of parenting a child with autism.

#### *Differences in Mothers and Fathers*

Several studies have reported that mothers and fathers of children with an autism spectrum disorder experience stress and coping in different ways (Davis & Carter, 2008; Gray, 2003; Hastings, 2003; Hastings et al., 2005) with mothers experiencing more stress than fathers (Herring et al. 2006). Hastings (2003), however, noted that mothers and fathers did not differ in their levels of stress but that mothers reported more anxiety than fathers did. Hastings revealed that child behavior problems and fathers' mental health were associated with mothers' stress; however, mothers' mental health was not associated with fathers' stress.

Davis and Carter (2008) discovered that problems associated with self-regulation skills (e.g., eating, sleeping, and emotion regulation) were associated with the stress of mothers of children with an autism spectrum disorder, whereas externalizing behaviors were associated with fathers' stress. Externalizing behaviors were associated with the types of behaviors that draw negative attention in public settings (e.g. yelling, screaming, and tantrums). Davis and Carter further noted that self-regulation skills might affect mothers more as they are generally more involved in daily childcare tasks (Noh, Dumas, Wolf, & Fisman., 1989). Likewise, Baker–Ericzén et al. (2005) noted that social interaction skills

significantly predicted stress in mothers of children with autism spectrum disorders due to these deficits being some of the most difficult to improve since they are central characteristics of the spectrum.

Other research has shown that the stress of fathers with a child with an autism spectrum disorder is affected by the stress of mothers. Studies by Gray (2003) and Hastings et al. (2005) noted that paternal stress related to their children with and autism spectrum disorders were affected by maternal stresses rather than the direct impact of their child's disability or behaviors. Gold (1990) researched the effects of social adjustment and depression in living with a male child with autism. Gold noted that research related to children with autism and their families was lacking in two specific areas. The first area was in identifying family processes and patterns unique to these types of families and, the second, whether or not there are specific differences in coping by family members of children with autism based on the gender of family members. With regard to gender differences, Gold questioned whether there were significant gender differences in families of boys with autism. Specifically, Gold questioned whether the mothers and sisters in these families demonstrated a higher incidence of depression and social adjustment problems than the fathers and brothers in these families. Results from Gold's study showed that parents of boys with autism scored higher than parents of typically developing children on measures of social adjustment using a specific social adjustment scale (SAS). Additionally, Gold noted that parents of boys with autism had greater problems with social situations, marital issues, and financial stresses and parents in families with children with autism adjust to common stressors to which parents with typically developing children are not exposed.

Regarding depression, Gold noted that parents of boys with autism showed significantly higher levels of depression over parents of typically developing boys. More specifically, mothers in this study scored significantly higher on depression than fathers did. The suggestion was also made in this study that fathers of boys with autism make sacrifices, such as compromising on career advancement and taking on more childcare responsibilities, which differentiate them from other fathers. Gold recommended additional research on gender differences within families having children with autism. Specifically, additional research was recommended focusing on the unique experiences of fathers and brothers, and the meaning of care giving and domestic work as it relates to different family members.

Gray (2003) further added to the literature with research focusing on coping and gender differences involving parents of children with autism. Through interviews conducted with mothers and fathers of children with autism regarding gender differences and coping, Gray noted that the greatest difference between mothers and fathers was the differing personal impact of their child's autism. The majority of the fathers in this study noted the severe difficulties that their child's autism presented for their families and typically claimed that their child's autism did not have a significant effect on them personally. Fathers, however, noted that their child's autism affected their wives. Gray also noted that a common role for fathers related to the concerns regarding their child's future.

Adding further information relative to gender roles and stress, Konstantareas and Homatidis (1992) examined parent involvement of 96 mothers and fathers of children with autism, children with intellectual disabilities, and non-disabled children. Parents were asked to report independently their direct involvement with child-related activities in six different categories identified as: dressing, feeding/meals, bathing/toileting, playing/recreation,

teaching/education, and bedtime routines. Parents of children with autism reported shorter interactions than the other groups, and mothers in all groups spent more time interacting with their children than did the fathers. In addition, the fathers of the children with autism reported spending the least amount of time with their children while mothers engaged more in care giving.

Blair et al. (1996) assessed parent perceptions of lifestyle changes related to having a child with autism. Using a telephone survey, mothers and fathers of children with autism were asked a variety of questions ranging from estimation of levels of optimism related to their child's ability to live independently, time spent with their child's therapy, financial burdens related to treatment, issues related to quality of time with their spouses, and effects on marriage. Fathers were found to spend significantly less time with their children than mothers. Blair et al. also noted that fathers had significantly lower response rates than mothers in participation in the survey. No significant differences were found in concerns associated with financial burdens, quality time with spouses, or effects on marriage.

#### Fathers and Sons with Autism Spectrum Disorders

Formal, qualitative research focusing on fathers and their sons with autism spectrum disorders is limited. Research conducted by Schwartzman (1983) assessed the relationships between fathers and their sons with Pervasive Developmental Disorder (PDD), and compared these relationships to those of fathers of typically developing children. Schwartzman observed and interviewed two fathers and their sons with PDD and 24 pairs of fathers and their typically developing sons. This research described the behavioral styles of fathers during interactions with an atypical son; their attitudes and feelings about their role as fathers; and their attitudes and feelings toward their sons. The results of this study indicated

that the two fathers of the sons with PDD had chosen not to have additional children because of the severity of their sons' problems. Both fathers also demonstrated distress over observing their sons' deviant behaviors and development. Both believed they were calmer and more controlled in contrast to their wives' emotional state. In addition, both fathers expressed concern over their sons' inability to take care of themselves and viewed themselves as the protector of their child.

Schwartzman (1983) reported that the greatest difference between these two fathers was their levels of acceptance and understanding of their sons. One father appeared more satisfied and at peace with his son's condition than the other. When compared to the fathers of typically developing sons, the fathers of the atypical sons were more controlling and hands-on. This was attributed to the types of behaviors exhibited by the children and the need for more physically active interactions. The fathers of the typically developing sons encouraged and facilitated more independent play than the fathers of the atypical boys did. Several limitations existed with this research, most notably, the small number of fathers of sons with PDD who were interviewed. Schwartzman noted that he encountered difficulty in finding children who met the specific criteria of being male and diagnosed with a PDD and finding fathers of such children who were willing to participate in the research.

Long (2005) focused on understanding fathers' experiences in raising sons with autism and conducted interviews with a homogeneous sample consisting of four biological fathers of sons with autism in the age range of three to five years. Specific themes emerging from this research included: concerns for the future; the experiences of stress; fathers' attitudes and sensitivity toward their children, identification of similarities; feelings of loss

with athletics; experience of talking to other fathers; and, the advice related to having a son with autism that these fathers would share with other fathers.

The fathers in Long (2005) expressed concerns regarding their children's ability to provide for themselves financially in the future. In addition, concerns existed regarding their sons' social and emotional development and being accepted socially by others. These fathers also discussed their experiences with stress, particularly with their inability to manage their sons' behaviors in social situations. Other areas of stress described included financial, marital, physical, and social factors.

The fathers in Long (2005) expressed attitudes of being sensitive and caring. Long noted that the responses given by the fathers in her study were important for clinicians, especially in discussing the strengths and positive qualities of children with autism and that clinicians may have a clearer understanding of father-child relationships and fostering self-confidence in parents of children with autism.

Fathers in Long (2005) identified similarities in themselves and characteristics as possessed by their sons with autism. Similarities identified by fathers focused on areas of deficits such as experiencing anxiety in new situations, difficulty in unfamiliar surroundings, sensory issues, and concerns with not making eye contact with others. Long noted that this may have been based on the desire of her participants to understand their sons' experiences.

Fathers in Long (2005) expressed feelings of loss regarding athletic involvement with their sons with autism. Long noted that the feelings of loss experienced by the fathers in her study may be related to shifting expectations from what parents expected from their sons prior to having autism. In addition, Long explained that the loss of sports-related dreams for

the sons in her study may be related to the stress parents reported regarding experiences with social activities.

The fathers in Long (2005) were all involved in support groups or organizations that advocated for individuals diagnosed with autism. Advice given by the fathers included becoming involved in every aspect of their children's lives, including learning about autism and the educational needs of their children.

### Conceptual Framework

A review of the literature related to parenting children with disabilities clearly identifies the difficulties that parents experience with regard to parental adjustment, coping, and stress associated with having a child with a disability. For parents of children with autism spectrum disorders, a review of the literature clearly recognizes that parents of autism spectrum disorders experience high levels of stress and that parents of children with autism spectrum disorders use a variety of coping strategies. These strategies may involve support from family and friends, social support groups, early intervention programs, use of professionals, counseling and therapy, and religion. In addition, differences also exist between mothers and fathers of children with autism spectrum disorders, with particular regard to how mothers and fathers experience stress and coping.

While the existing literature provides insights into the experiences of parents of children with autism spectrum disorders, a limited amount of research and knowledge exists with specific focus on the experiences of fathers of children with autism spectrum disorders, with an even greater scarcity of research on the particular experiences of fathers and sons with autism spectrum disorders. Long's (2005) research addressed only a few participants and a narrow age range in the sons as did Schwartzman's (1983) research which included

only a small number of fathers of sons with PDD. The limited number of studies suggests there is a continuing need to explore and understand the emotional and psychological aspects of fatherhood in men who have sons with autism spectrum disorders.

As a school principal who has worked directly with parents of children with disabilities and more specifically with parents of children with autism spectrum disorders, I have been able to observe the emotional struggles and difficulties that parents experience. As part of these observations, I have observed limited participation of fathers involving their children's educations. My experiences with fathers of children with autism spectrum disorders have involved observations between fathers and their sons. These experiences and the review of the literature have been helpful in developing an initial framework of understanding. This study was designed to explore the experiences of fathers of sons with autism spectrum disorders with the goal of providing additional insight into how these fathers view fatherhood. The research previously conducted by Long was used as a guide for designing this study. Several of the questions identified in Long's study have been adopted for use in this study. In order to gather additional data and understanding for this study and construct new understandings into this phenomenon, I constructed my interview questions in three categories relating to diagnosis, fatherhood, and changing experiences.

I constructed questions under the category of diagnosis to provide opportunity to gather additional understandings about each of the participants and their sons, their sons' diagnoses, and the concerns and worries that fathers and parents have regarding their sons with an autism spectrum disorder. Questions under the category of fatherhood were framed to provide new knowledge and understanding about the experiences that the fathers in this study had with their own fathers, gratifications and difficulties associated with having a son

with an autism spectrum disorder, relationships with other fathers, and responsibilities associated with being a father of a son with an autism spectrum disorder. Last, I constructed questions under the category of changing experiences to explore how fatherhood is affected by having a son with an autism spectrum disorder and how having a son with an autism spectrum disorder changes fathers' views on fatherhood.

## CHAPTER 3

### METHOD

This chapter identifies and describes the research design used in conducting this study. The descriptions of six fathers who were interviewed and their sons who have autism spectrum disorders are presented. A detailed description of how data were collected using interviews with participants and how transcripts were coded to develop themes representing the experiences and perceptions of the participants concludes this chapter.

#### Research Design

A qualitative, phenomenological research approach was used to explore the following research questions: (a) What are the experiences among fathers of sons with autism spectrum disorders? And, (b) How do fathers' perceptions of fatherhood change through the experience of parenting a son with an autism spectrum disorder? A phenomenological approach for conducting this study was chosen for three reasons. First, qualitative researchers using phenomenological methods seek to ask questions to understand the meaning, structure, and essence of the lived experience of a phenomenon for an individual or group of people (Merriam, 1998; Patton, 2002). In this study, the phenomena of interest were the experiences and perceptions of fathers of sons with autism spectrum disorders and how the perceptions of fatherhood changed as a result of having a son with an autism spectrum disorder. Merriam and Patton explained that the data used in phenomenological research come from the participant and investigator's firsthand experiences. My own first hand experiences of interacting with fathers of sons with autism spectrum disorders have been included with the

first hand experiences and perceptions of fathers of sons with autism spectrum disorders who participated in this study. My experiences related to this phenomenon were not as a father of a son with an autism spectrum disorder, but as a school principal who had multiple experiences in interacting and observing families of children with disabilities, with specific experiences of interacting with mothers and fathers of children with autism spectrum disorders.

Second, researchers using a phenomenological approach focus on how human beings make sense of their experience and then convert that experience into consciousness as individuals and as a shared meaning for the group. This study examined the perspectives of each participant as a father of a son with an autism spectrum disorder and sought shared meanings for the group as a whole. In order to find and capture the shared experience of this group, sets of interviews were conducted with each father, asking questions that led them to share their perceptions, feelings, and experiences related to having a son with an autism spectrum disorder. The interpretations of shared meanings were developed through the identification of themes that existed across the entire group of participants from these interviews along with the reflections from my experiences as a school principal.

Third, this study was designed as an extension of the research conducted by Long (2005). Long used a phenomenological approach to explore the experiences of fathers of sons with autism, ages three to five years.

### Participants

The six fathers who volunteered to participate in this study were biological fathers who have sons with autism spectrum disorders excluding Rett syndrome and CDD and were

currently married to their sons' mothers. Long (2005) also used biological fathers who lived with the mothers of their sons with autism.

A total of six participants were chosen and secured for this study. Participants were identified first from personal and professional relationships. The choice to study a purposive sample in-depth is consistent with phenomenological research. Creswell (2007) noted that a general guideline in qualitative research is to study a few individuals and to collect extensive detail about each individual studied. Further, Creswell noted that in phenomenology, numbers of participants have ranged from one to hundreds of participants. The current sample of fathers is unique in several ways. All the fathers in this study were currently married to the mothers of their sons. With divorce rates of parents of children with an autism spectrum disorder estimated to be around 80 percent, this group of fathers may possibly represent an anomaly when compared to other fathers of sons with autism spectrum disorders (Bolman & Burns, 2006). The fact that these men stayed in intact relationships with their families allowed for initial exploration of what may have contributed to their ability to stay. In addition, the fathers who participated in the study were at three different phases of life experiences and developmental age ranges with their sons with autism. Two of the fathers had sons in a 5-7- year age range, two in, 10-1- year age range, and two in a 15-17- year age range when the research interviews began, which allowed for examination of changes over time, as the sons with autism grew older.

One of the six fathers participating was secured through both a personal and past professional connection. I met this father when I was an assistant principal at a previous school. In addition, a request for recommendations for names of parents or possible contacts was sent through an email to the Director of Exceptional Children for Catawba County

Schools. Email was used as a method of communication due to convenience and ability of others such as the Director to forward a request and information related to the research to other contacts.

The Director of Exceptional Children forwarded email requests containing attachments of a letter of consent (Appendix A) and a letter of explanation (Appendix B), to a contact at the local chapter of the Autism Society of North Carolina and to an advocate for parents of children with severe disabilities living in a neighboring county. Both contacts forwarded the emails and attachments to fathers and families of children explaining the proposed research study. A reply email of interest was received from participants. In turn, a response with a return email thanking them for their interest and a telephone call then occurred.

The Institutional Review Board at Appalachian State University approved the proposed study. As required by the Institutional Review Board, all participants were provided with a complete and thorough explanation of informed consent. The informed consent contained detailed procedures of the research, risks associated with participation, benefits associated with participation, the extent of anonymity and confidentiality provided to participants, the absence of compensation associated with participation, and an explanation that participants were free to withdraw from the research at any time without penalty or harm.

Descriptions of participants and their sons were created from the information gathered during interviews. During initial interviews, information was gathered about the identity of each father, their sons with autism spectrum disorders, occupation, a description of the sons' disabilities, and characteristics related to the sons' autism spectrum disorders.

Pseudonyms have been used for all participants, family members, and their sons throughout the study. Table 1 provides a brief description of the fathers and their sons.

Table 1

*Participants and Descriptions of Sons with Autism Spectrum Disorders*

Father	Occupation of Father	Son(s)	Autism Spectrum Disorder	Description of Sons with Autism Spectrum Disorder
Tim	Research Technician	Matthew (age 6)	Autistic Disorder	Limited verbally and often non-interactive with others, high level of sensory issues related to specific sounds such as high tones, very strict dietary concerns and currently on a gluten free, casein free diet (no wheat or dairy products).
Edward	Early Childhood Program Director	Tommy (age 7)	Asperger's syndrome	Difficulty with social skills and transition from one situation to another, high-level of artistic ability.
		Nathan (age 5)	Autistic Disorder	Mostly non-verbal with some development of basic communication skills, often engages in echolalia and prone to make constant noises and flap hands, obsession with food.
William	Retired Military Computer Technology	David (age 11)	Asperger's syndrome	Originally diagnosed with Autistic Disorder but had to be reclassified as having Asperger's syndrome, difficulty with social skills and interactions with others, exhibits echolalia, mimicking of others, sensitive to noises
Brad	Adolescent Counselor	Joseph (age 10)	Autistic Disorder	Difficulty with social skills and sensory issues related to touch, difficulty with verbal communication and transition from one activity to another
Sam	Technician – Information Technology	Jacob (age 17)	Asperger's syndrome	Difficulties with social skills and prefers to be alone, difficulty handling change
John	Cable Manufacturing	John, Jr. (age 16)	Mild Autism	Some difficulty with social interactions, obsessive compulsive tendencies with order and dress, some difficulties with some fine-motor skills, high musical talent

## Data Collection

Collection of data for this study began with formal transcripts obtained through semi-structured interviews of each father. For this study, semi-structured interviews are defined as a standard set of open-ended questions (Appendix C). As interviews occurred with each participant, probing or follow-up questions occurred creating the semi-structured interview format. Probing and follow-up questions were inserted to encourage participants to expand on responses or provide clarification regarding responses. Interview questions from the Long (2005) study (Appendix D) served as an initial guide in helping create the questions for this study. Questions from member checks were added from two fathers of boys with autism spectrum disorders with whom I had a professional relationship as an elementary principal. These two fathers did not serve as participants due to my principal/parent relationship with them at the time of creating questions. Each agreed to review questions and provide suggestions for additional questions. After reviewing all questions, both fathers agreed it was important to add a question related to how fathers were involved in their sons' educations.

Fathers in this study were interviewed three separate times. In the first interview, fathers were asked semi-structured interview questions. The second interview involved a review of transcripts and clarifications from the first interview. The final interview concluded with a review of the draft from the results and discussion chapters. Interviews conducted with five of the participants during the first set of interviews occurred in local restaurants with convenient locations for the fathers during their lunch hour or work schedules. One interview occurred in the father's home on a Saturday morning. A digital recorder was used to audiotape each interview. After each interview was completed, fieldwork memos were

recorded using a digital audio recorder to record any ideas about the interview or about the research. Two examples of field memos are included in Appendix E and Appendix F.

After each interview, verbatim transcripts were completed. Transcribing verbatim transcripts was a valuable part of the research process. This gave an opportunity to thoroughly review the content of each interview and begin to process each of the interviews in a written manner. All interviews and transcripts from the first round of interviews were completed before any second round interviews occurred.

After the first set of interviews and transcripts was completed, sets of transcripts were emailed to each father. Follow-up telephone calls were scheduled with each father. Telephone interviews were used for the second set of interviews as a method to save time via electronic communication and reduce travel and meeting time. Telephone conferences ranged on average from 20 to 45 minutes in length. Second round interviews over the telephone followed the format of going through each interview question and asking fathers to verify that their responses were accurate.

Following the second round of interviews, fathers were emailed copies of the results and discussion sections to review prior to meeting. During the third interview, all writings were reviewed in detail with any follow-up questions for clarification from the transcripts from the first interviews. These interviews were valuable in garnering final responses from the fathers and providing final clarifications towards interpreting their views and experiences.

In order to establish rapport with the fathers in this study, all interviews occurred in an informal setting over breakfast, lunch, or dinner. This occurred to help ease any tension and create a more relaxed environment as well as to provide convenience for the fathers. In the final interviews, the fathers noted that the mealtime setting, particularly the lunch hour,

was convenient for meeting. In addition, the fathers in this study shared that the most important factor in establishing rapport related to interest in them as fathers of sons with autism spectrum disorders. They each reported that they believed this study was an important project that might help others with regard to autism.

By taking an interest in each of these fathers and their sons, an initial trust was established allowing the start of a personal conversation and connection within the initial interview. I listened to these fathers and allowed them an opportunity to establish themselves in a position of extreme importance in their lives as men, spouses, and fathers. Glesne (1999) noted that while “researchers do not wittingly assume the role of therapist, they nonetheless fashion an interview process that can be strikingly therapeutic” (p. 127). With the degree of emotion that I have witnessed in fathers’ expressions in my own professional experiences, I expected there to be some degree of emotional expression in these interviews, therefore making it important that the set up of the initial interviews occurred in the most comfortable, non-threatening setting possible.

### Data Analysis

Informal data analysis began immediately after each interview through the recording of personal reflections about the interview. These recorded reflections were generally completed during the drive from an interview to home or back to work (Glesne, 1999). Field memos included my immediate thoughts about each participant and their perceptions and experiences of having a son with an autism spectrum disorder. Information and specific details were recorded related to our meetings, such as location, setting details, and any thoughts about improving the interviews. As a final piece to these memos, analytic notes and

information related to each participant were recorded that may have needed further exploration or clarification.

Formal data analysis began after completing the first round of interviews with all fathers. Audio recordings were converted into written transcripts in Microsoft Word. All field memos were included in the coding process as a guide to begin identifying the commonalities shared across participants. As Patton (2002) noted, at the end of formal data collection, primary sources of analysis come from interview questions and the analytic insights emerging from the data.

Interview transcripts and field memos were imported into NVivo7 (QSR International, 2006), a computer-assisted qualitative data analysis software (CAQDAS). NVivo7 was used to assist in managing transcript data for developing and organizing codes, themes, and patterns in an efficient and timely manner. NVivo7 also enabled the assignment of visual written codes in a filing system and key points to be highlighted within text. While NVivo 7 contained Boolean search engines designed to find patterns within text and view information in a variety of contexts, this option was not used, preferring instead to search the data more personally. Merriam (1998) noted that the most frequent concerns about NVivo and other forms of CAQDAS are that the tools may change the nature of qualitative research by distancing the researcher from the data and producing errors in analysis.

Glesne (1999) noted that analytic files are organized by generic categories such as interview questions, people, places, subjects, titles, and quotations to help researchers begin to store and organize their own thoughts and the thoughts of others. Initial coding of data began by sorting interview data into similar files or categories following each question. After reading completely through each set of transcripts individually, each interview question

was taken separately with each set of responses to each question from each father in a simultaneous fashion to highlight common phrases, words, and quotes from the responses. While reading each question and highlighting responses, similar pieces of transcription data and reflection data were sorted and categorized into organized groups and identified under initial codes. Data broken down into initial codes and sub-codes were organized into themes.

In order to demonstrate how this process was organized an example from one of the questions from interview transcripts and the coding that occurred related to this question has been included. Table 2 shows the highlighted responses from fathers, the initial coding categories and sub-codes assigned and then the focused code that determined themes.

Table 2

*Example of Coding Method*

Highlighted Responses	Initial Codes/Sub-Codes	Focused Codes (Possible Themes)
<p>R. aside from the future</p> <p>R. what would happen to him if I wasn't around</p> <p>R. what's going to happen when he grows up</p> <p>R. what his life is going to be like</p> <p>R. how he is going to be taken care of</p> <p>R. what is going to happen to him when we are gone</p> <p>R. what is going to happen to him when we are not around</p> <p>R. where he is going to end up</p> <p>R. hold a job</p> <p>R. be self-sufficient</p> <p>R. can he be self-sufficient</p> <p>R. future, his future</p> <p>R. how independent he will be able to live his life</p> <p>R. how he would get along and end up</p>	<p>Future</p> <p>Self-sufficiency</p> <p>Employment</p> <p>Independence</p>	Concerns for the Future
<p>R. socially interacting with people</p> <p>R. worried about them emotionally</p> <p>R. he will regress</p> <p>R. being able to communicate</p> <p>R. trouble learning to read</p> <p>R. to get so much education into them where they have basic reading functions</p> <p>R. academic worries</p>	<p>Socialization</p> <p>Communication</p> <p>Education</p> <p>Academics</p>	<p>Concerns for</p> <p>Communication and Social Skills</p> <p>Cognitive Abilities</p>

## CHAPTER 4

### RESULTS

The purpose of this study was to expand on the research of Long (2005) and address the gap in the research literature related to the role of fathers of children with autism spectrum disorders, the intimate relationships fathers experience with their sons who are diagnosed with autism spectrum disorders, and changes in their perceptions of fatherhood. This chapter includes two major sections. In the first section, detailed narrative descriptions of each of the fathers involved in the study are presented along with a description of their sons with autism spectrum disorders. The first section addresses the research question: What are the experiences among fathers of sons with autism spectrum disorders? Narrative descriptions provide information about the fathers' experiences with their sons and the relationships that the fathers in this study have with their sons. The information related to their personal lives provides a window into the phenomenon of being a father of a son with an autism spectrum disorder.

In the second section, six major themes from the interview data are presented. These themes are: 1) concerns for their sons' future; 2) behavioral impacts of the son on family social life; 3) experiences with their own fathers; 4) involvement in their sons' education; 5) differences in parenting their sons versus typically developing siblings, and 6) changing views as fathers. These themes provide an explanation of the commonalities shared across participants. Quotations are used from interview transcripts to support each theme. The first five themes in this section provide information on the experiences of fathers of sons with

autism spectrum disorders. The final theme, changing views as fathers, provides information on how the fathers perceived they have changed as a result of having a son with an autism spectrum disorder.

### Narrative Descriptions of Participants and Experiences with Sons

#### *Tim and Matthew*

Tim is a 41-year-old father of two boys. He is a research technician in cable manufacturing and is married to Faith. Tim shared that Faith “is a stay-at-home mom [and] she never has a day off [as a mother of a son with autism].” Tim shared that he believed he and Faith “have a very neat family life.” He added that he and Faith have a very strong marriage and that they “are opposite in some ways as in likes and perceptions and maybe points of view. One thing we do agree upon is how we view our children as a gift from God, and we want to provide them with a love for God.” Tim and his family are very involved in their church and started attending church more regularly a few years ago, when Tim's mother passed away and he and Faith had learned of Matthew’s diagnosis of autism. At the time, attending church was a piece of Tim's coping for two very difficult events in his life and he shared that “instead of leaning on ourselves, we are leaning on God.”

Tim described his boys as “polar opposites” because of the range of differences in their abilities. Tim’s youngest son, Matthew, is six years old and diagnosed with autistic disorder. Tim described Matthew as being the “perfect baby” because he was always quiet and never cried a great deal. As Matthew began to grow and develop, Tim and his wife began to notice that Matthew was seldom interactive with others, had very limited responses verbally, and appeared to ignore verbal commands or responses from those around him. In the beginning stages of observing Matthew’s behaviors, Tim noted that he and his family

began to wonder if Matthew had hearing issues. Tim described Matthew at present as being very quiet and mostly nonverbal.

Tim also described Matthew as having atypical social behaviors. He had sensory-related issues with certain sounds. If Matthew heard a siren, helicopter, or sounds with a high pitch, he might hold his ears and scream. In addition, Matthew also had severe food-related issues and dietary constraints. He was on a gluten-free, casein-free diet:

Wheat and dairy have a big effect on [Matthew's] diet. It is like sticking a syringe of morphine into his arm, and he is high as a kite. It took months to get him off the milk and wheat; he would drink a gallon of milk a day when he was three. When we got him off that morphine high he was coming out and starting to look around more. It was like being around someone who was completely stoned before that.

Moreover, Tim described Matthew as being physically healthy and extremely active as a child. He was described as a child who had no fears and had a tendency to run. Tim noted that several times, Matthew had run into the street. Matthew also loved to swim, particularly in deeper water, and appeared to have no fear of the water. Tim believed that the deeper water provided pressure on Matthew's ears, which he liked because of his sensory issues.

When speaking of Matthew, Tim characterized him as his "special son." On a very personal level, Tim added that Matthew loved to play and especially wrestle in a rough manner with his father. Matthew also "loves trains... But his interest has shifted. [When he was much younger,] he loved rolling the wheels [but noted that this was] not the appropriate level of play." Tim felt very disconnected from his son when Matthew was diagnosed with autism. He was not sure what the cause of the disconnection was or how to describe it. He

added that on a family trip to the mountains of North Carolina, he was able to spend a few very important days alone with Matthew that helped him to begin to establish a bond with his son. Tim described this time in the following way:

We just hung out for two days pretty much; Matthew and myself. We got a bond that was unbelievable. Faith noticed this in the weeks that followed that we got this bond. It was a beautiful thing to have this early on when he was young. I don't know what it was or how that happened. It was I guess me taking the step. The situations, circumstances, were just perfect for me and Matthew to get this click, this bond together. So we have had it ever since, I believe. It has just been amazing.

At the time of the interview, Tim believed that he and Matthew had a very close relationship with one another. It had been gratifying for him as a father to know that his son acknowledged his existence when he would come in the door and Matthew would look at his father and communicate with him. This was something that had developed over time as Matthew's communication skills had begun to progress. Tim believed that the lack of acknowledgement was not because of a lack of love between him and his son, but because of the neurological disorder, that affected his son's communication abilities.

*Edward, Tommy, and Nathan*

Edward is a 36-year-old father of three boys. He is an early childhood program director and married to Susie, who worked outside of the home at the time of the interview. However, in the early years of rearing children, she stayed at home. Edward believed that the time that Susie stayed home with their children was a benefit to the entire family, especially in attempting to deal with the behaviors of two sons on the autism spectrum. Edward added that he and his wife love each other and wanted to have a family with one another. He stated,

"we [he and Susie] have a commitment [to one another] and both wonder, if something were to happen to the other one, if it would weaken our effectiveness [as parents]. We really tag team one another."

Edward was born in Virginia where grew up in a large family with six siblings. He was a very large man in stature, and said that people assumed that he played sports, usually football. Instead, Edward stated that he was "the biggest dork in the world [and played] Dungeons and Dragons with [his] brothers." He added that because one of his brothers lived next door to him, he could be at home very quickly if needed, or he could slip next door and play a board game. Edward believed the fantasy game of Dungeons and Dragons gave him an opportunity to escape from reality and to have conversations in a fantasy world.

Edward's oldest son, Tommy, was seven years old, and diagnosed with Asperger's syndrome. Edward described Tommy as removed socially from all situations. Edward also noted that when others looked at Tommy, they did not know that he was different from other children. The most difficult issues that Edward faced with Tommy dealt with transitions from one situation to another. In addition, Tommy also has some learning difficulties involving processing information and problem solving.

Social skills were a major deficit for Tommy, especially when he attempted to react to other children or attempted to get attention. Edward added that when Tommy began school, he had great difficulties with the requirements and structure that existed in his classroom setting. Regarding Tommy's social skills, Edward told a story about his son kissing other children, all other children, in his classroom because of his belief that this was a way for them to like him or want to interact with him. Tommy was also very artistic.

Edward shared that Tommy could do remarkable drawings and never lifted his pencil from the paper.

Edward's middle son, Nathan, was five years old and diagnosed with autistic disorder. Edward and Susie had Nathan tested for hearing issues as a small child, believing that he might be deaf, due to his lack of response and limited speech. Prior to starting school, Nathan had been mostly non-verbal. At the time of the interviews, however, Nathan was starting to develop some basic communication skills such as naming items in picture books, recognizing names of others, and identifying basic colors. Generally, Edward noted that Nathan responded with only one- or two-word responses. Nathan also had some echolalia and often repeated or mimicked sounds, statements, or information he heard from others. In addition, he often made noises or sounds and would flap his hands. Edward noted that Nathan did well with gross motor skills; however, he had great difficulty with fine motor skills such as holding pencils and crayons.

Edward described Nathan as “fearless” and that he liked to jump off high areas. He appeared to have immunity to pain, which might be related to sensory issues. Nathan was prone to run away from other adults. Running away often made it difficult to take him outside in an area that did not have a fence, and as a couple, they often had nightmares of Nathan getting away from them. Nathan was obsessed with certain foods, especially with fruits such as grapes and bananas. His obsessions, however, were not with eating foods, but rather in hiding them and playing with them. It was common to find grapes and bananas stashed in the house in unique places or for family members to step on them.

Edward's youngest son, Michael, age two was typically developing. After having two sons on the autism spectrum, Edward described Michael as "relatively normal" and added

that having him, as a son was "an easy thing." Edward said, "Not to minimize him, but I feel he is the least of the three. As long as he is developing fine, we can handle it; whatever he's got."

While Edward had two sons on the autism spectrum, he was much more concerned about Nathan than Tommy due to the severity in Nathan's differences especially with his deficits in communication skills. Because of his sons' diagnoses, he has had to deal with several emotions and has been very upset as a father. Edward added that, as a parent, he said to himself, "How bad is this disability? [and] I had a lot of questions about how they could function in society. [With Nathan,] I just wanted him to speak." Edward stated that now, "I think I am more accepting of the situation...I think I am over it, but I thought, 'Is there something wrong with me or wrong with my child?' I am over that, [but] it was there."

#### *William and David*

William is a 53-year-old father of four daughters and one son. He is retired from the military and is currently continuing his education for a new career in the area of computer technology. William is married to Beth who worked out of the home as a nurse. William's four daughters were all from two previous marriages and were ages 36, 32, 31, and 29 years. He is the only father participating in the study who has grandchildren. William's son, David, is age eleven years and diagnosed with Asperger's syndrome. Prior to the diagnosis of Asperger's syndrome, David had a diagnosis of autistic disorder. This diagnosis was changed due to David's advancements in communication over the past several years.

William is from California and described himself as the son of a Navy man. When he was age 16, he ran away from home, and at age 17, he joined the U.S. Marine Corps. William remained in the military for 16 years until an accident created a medical disability

and discharge from the service. William is a Vietnam veteran and he often wonders if something he was exposed to while in military service caused his son to have an autism spectrum disorder. William stated, "I wondered if something in me [caused this]? I have been radiated, [exposed to] chemical, biological experiments of the government. There is a lot of stuff. I am one of 18 guys that are still alive [from my Marine Corp unit]. I wondered if it came from me. A lot of my friends had cataracts or cancer [from exposure to] Agent Orange." William also shared that he had to come to terms with his own thoughts about what may have been the cause for David's autism. He shared that his questioning of causes was counterproductive in helping his son. He stated that after he stopped doing this, he was able to start "to learn how to handle it; [focus on] what I needed to know [and] how to better change to help him."

TEACCH in Asheville, North Carolina diagnosed David with autistic disorder. As a young boy, David had great difficulty in interacting with others and often needed some sort of prompting to do so, especially with other children. William described David as a very shy boy who appeared to be very intimidated around others. David also exhibited a great deal of echolalia and mimicked others. His father described him as the "premier sound effects man." David was also very sensitive to sounds, especially loud noises. David was also born with complications during the delivery process. Beth had to have a Caesarean section due to the umbilical cord being wrapped around David's neck. William explained that when David was a small child he had some peculiarities. When William and Beth took him to the pediatrician and asked about his behaviors, the pediatrician responded with comments such as, "He will grow out of it." As a small child, David had behaviors such as "rag[ing] out" and difficulty

with motor skills, especially in going up and down stairs. It was not until the age of two years that he began to show any signs of intelligible speech.

William believes that David is like many other typical boys that he knows. He is interested in camping, hunting, fishing, shooting guns, and riding motorcycles. When David was younger, his extreme sensitivity to noise was very frustrating for William due to William's own love for motorcycles. David now rides with William on his motorcycle because wearing earmuffs has greatly reduced the noise and sensitivity issues. To make the experience of riding easier for son and father, William has added a sidecar on his motorcycle.

#### *Brad and Joseph*

Brad is a 42-year-old father of a son and daughter. He is a counselor for adolescent boys and works with child protective services. Brad is married to Cindy, a nurse. He noted that he is very fortunate to have a wife who is a nurse because she is the one person in the household who takes care of the children when they get sick. Brad's son, Joseph, is 10 years old and diagnosed with autistic disorder. His daughter is age four and developing typically.

Brad's father was in the military and attended military school prior to Brad's birth. Brad and his father have a very close connection since Brad's father reared him after his mother abandoned his family when he was young. Brad added that he grew up on the coast of South Carolina where his father served as a postmaster for the United States Postal Service. He and his father are both huge football fans and love Clemson University football games.

Brad noted that around the age of 18 months Joseph was mostly non-verbal, and Brad believed that the child would simply be late in learning to speak as compared to other typically developing children. When someone would call Joseph's name, he would often be

nonresponsive, leading Brad and Cindy to believe that he could not hear and might need testing by an audiologist. The audiologist also commented that their son would be a “late talker.”

Brad described Joseph as being uncomfortable with social situations and socialization. He typically would not make eye contact with others and mostly liked to play by himself. Brad noted that Joseph was “really not [the] sit in the corner, flap his arms, that kind of thing” boy with autism. However, he did have sensory issues and typically did not like to be held or touched. As a younger child, Joseph would mimic others with words and actions. While Joseph had difficulty speaking he also had his own language and communication methods. Brad noted that Joseph pointed and made gestures and sounds when he wanted certain items or objects.

From a safety standpoint, Brad always wanted Joseph closely monitored because Brad knew that Joseph would wander off from whomever Joseph was around at the time. Brad and Cindy had serious concerns about Joseph wandering into the street. Brad added that Joseph had “non-stop energy” and that the constant energy and attention he required was difficult. Joseph has great difficulty with transitions. Brad noted that because of the constant attention Joseph needed, as a parent, he was motivated to stay healthy.

In the early stages of diagnosis, Brad had difficulty with what his son's diagnosis actually was on the autism spectrum. He stated, “[he and Cindy] went through all the confusion over is it autism, is it PDD, the whole thing. In hindsight, we realize that it doesn’t really matter where he is on the [spectrum]. It does not matter what you call it. It does not matter whatsoever. All that matters is that he learns differently and we have to adapt to it.” Brad stated that when he realized that his son was different, “That's what comes crashing

down on you is all the things that you want for your kid. You are like, 'Is this ever going to happen?'"

As parents of a child with a disability, Brad and Cindy went through a period of denial. Brad described his reaction to learning about his son's diagnosis "like [I] had been hit by a train...like my heart had stopped." As a positive, Brad commented that he loved to read to his son and tried to do this every day. One of Joseph's favorite stories is *Good Night Moon*. He has to hear it every night before going to sleep.

#### *Sam and Jacob*

Sam is a 47-year-old father of two boys. He is a technician in information technology and married to Sarah. Sarah had been a stay-at-home mom but works as a part-time teacher at a local charter school. Sam's oldest son, Jacob, is age 17 and diagnosed with Asperger's syndrome and Attention-Deficit-Hyperactivity Disorder (ADHD). Sam's youngest son, Peter, is fourteen and typically developing.

Sam is a great lover of sports since he played football at Davidson. He later transferred to UNC-Chapel Hill where he met Sarah. Sam and Sarah have lived in multiple places around the country from Houston, Texas to Knoxville, Tennessee. He and his family are actively involved in their church and want both sons to have a strong faith in God. Sam attributes a great deal of his ability to cope with life's events to his faith in God.

Sam described Jacob as being a very strong-willed individual. Sam noted that Jacob was a higher functioning child with autism and described his son as mostly being satisfied with being alone; however, he did have times when he wanted to be in the company of others. Usually this occurred when Jacob had the desire to make things happen on his own

terms. Sometimes, Jacob had difficulty handling change and seemed to do better if prepared for changes in advance.

Around the age of one year, Jacob had difficulties learning to speak. As he entered daycare within the next year, he was still not communicating as well as expected for his age, and it was difficult to communicate with him. Sam shared that in the preschool environment, Jacob was hard to instruct and would hit other children. Disruptions in the preschool setting caused his parents to make the decision to remove him. When Jacob began school in kindergarten, Sam and Sarah enrolled him in special education classes. As Jacob began to experience successes, the school provided opportunities for Jacob to be involved in mainstreamed, regular education classrooms. For most of his elementary and middle school years, Jacob was involved in a combination of special education and regular education classes within the school setting.

Sam attributed a great deal of Jacob's success to his mother. As an educator, Sarah was Jacob's primary advocate in educational settings. Like many other boys, Jacob liked cartoons and video games. Sam noted that Jacob did not like to get hot. This was a deterrent to him playing sports. Jacob loves to fish and swim. Sam and his family live next to a cove on one of the lakes in western North Carolina. This environment gives Jacob a fantastic opportunity to fish and swim during summer.

*John and John, Jr. (JJ)*

John is a 48-year-old father of two boys. He is employed by a cable manufacturing company and married to Heather. Heather works as an educator at the elementary school level. John's oldest son, JJ, is age sixteen years and diagnosed with autism. John's youngest son, Paul, is fourteen and typically developing. As a baby, JJ cried nearly all the time. John

and his wife had to take shifts with him in order for everyone to try to get some sleep because of all the crying. John and his wife had noticed that around the age of two years JJ had limited verbal skills and knew only a few words. Additionally, he appeared to begin to regress, losing skills he had previously learned.

After visiting several doctors and specialists regarding these behaviors, John and his wife discovered that JJ had problems having bowel movements, causing major discomfort and other health issues for him. In addition, John noted that his son would flap his hands and turn in circles. JJ began school in a public-separate school setting designed for children of special needs. Originally, John and his wife did not want their son to attend school in this setting nor did they believe it was the right location due to the number of children with intellectual disabilities also attending the school. Time would change their opinions about the importance of starting their son off in this manner after they began to see some of the progress that he made with behaviors and communication. Around the first grade, JJ transferred into the regular education setting for elementary school children and was served through the exceptional children's program.

John described JJ as a lover of music with the ability to play several instruments. John also noted that JJ is "very black and white" on issues as well as very shy. JJ is obsessive about things in his life needing to be in order. In particular, his father described him as being very meticulous with his appearance, but he sometimes has trouble dressing. Buttons can cause him problems. He often has to have help with such items from his parents. As a young man, JJ was somewhat of a perfectionist and, when he was younger; he would often get upset and cry when things were not as he thought they should be.

John noted that he was very proud of JJ and believed that as JJ had matured, this had also helped with the behaviors that were associated with his son's autism. He noted that JJ was learning to drive and that they were exploring options for a car for him. There were concerns that he was having difficulty, not with driving, but with directions and navigating from one place to another. If he were to be able to drive, it would most likely be only for short distances between familiar places. John believed he had the best of both worlds with his two sons because of his love for both sports and music. He added that his son, Paul, was his athlete and his son, JJ, was his musician. John stated that it had "been pretty gratifying that JJ is good with music. I can take a song and say, 'John. How do you play *Let It Be.*' Remember that song from the Beatles? Well, he showed me the notes and I can sit down and I can play a little bit on the keyboard because of him and he can play the keyboards. He has taught me that."

#### Themes from Interview Data

The first five themes identified in this section from the interview data address the first research question: What are the experiences of fathers of sons with autism spectrum disorders? The final theme, changing views as fathers, provides information on how the fathers perceived they have changed as a result of having a son with an autism spectrum disorder. These themes are summarized in Table 3.

Table 3

*Identification of Themes and Summary of Findings*

Themes	Summary of Findings
Concerns for their sons' future	Concerns for their sons' futures existed regarding abilities to be independent as adults. Concerns intensified with the fathers of the sons in the elementary and middle school age ranges due to greater issues with communication skills, cognitive abilities, and social issues.
Behavioral impacts of the son on family social life	Fathers expressed frustrations regarding the negative behaviors of their sons and the impact of these behaviors on their family social life, both past and present. Intensities of behaviors appeared to lessen as the boys in this study progressed in age.
Experiences with their own fathers	Fathers experienced positive relationships with their own fathers or father figures during their childhood experiences. Fathers attempted to emulate characteristics or actions from their own fathers with how they viewed themselves as fathers and how they interacted with their sons.
Involvement in their sons' education	Fathers were involved in their sons' education. Fathers assisted with activities such as reading and homework with their sons. Fathers with the youngest sons had a greater focus on their sons learning to read and the development of literacy skills.
Differences in parenting their sons versus typically developing children	Five of the six fathers believed they parented their sons with an autism spectrum disorder differently than their other children. Fathers had higher expectations related to social skills, behaviors, and cognitive abilities for their other children.
Changing views as fathers	Fathers expressed a variety of changes including feelings of personal growth, development of patience, becoming more tolerant, understanding challenges, and becoming more responsible as a parent.

*Concerns for Their Sons' Future*

All interviews began by asking fathers about their sons, how they learned their sons had an autism spectrum disorder, and when they had learned their sons had an autism spectrum disorder. Each of these questions gave specific details and information about each one of their children, family histories, and personal information related to their overall family life and primarily focused on learning about information and issues surrounding their sons' diagnoses. Fathers were also asked to describe their reactions to learning that their sons had an autism spectrum disorder or to discuss any concerns or worries, and to share their hopes and dreams for their sons. All of the fathers in this study expressed concerns about their sons' futures. These concerns primarily pertained to their sons' abilities to function in society and to be independent as adults. All six fathers worried about who would take care of their sons in the future, especially when they, as parents, were no longer able to do so because of aging or death. Concerns varied relative to the sons' ages. While the fathers of the older sons continued to have concerns, the severity or intensity of concerns around educational needs did not appear to be as great as the concerns of the fathers of the boys who were in elementary or middle school. Interviews with the fathers of the older boys revealed that they had observed significant progress and success with their sons' communication, cognitive abilities and acceptable behaviors as their sons had grown older.

The fathers' specific concerns also varied relative to the ages of their sons. The fathers of the two early elementary age boys were primarily concerned with communication and educational needs. The fathers of the sons in the middle school age range, however, were more concerned with their sons' self-concepts and who would take care of their sons when and if they were no longer able to do so. The fathers of the two oldest boys, who were

closest to high school completion, had specific concerns related to their sons' functional independence (e.g., driving licenses, post-secondary education, employment, and independent living). Table 4 identifies the differences in concerns across the age ranges of the sons.

Table 4

*Differences in Fathers' Concerns Across Age Ranges of Sons*

Fathers	Sons	Age Ranges	Concerns
Tim Edward	Matthew Tommy Nathan	Elementary School 5 – 7 years	Communication abilities Basic Educational Needs Literacy Skills
William Brad	David Joseph	Middle School 10 – 11 years	Ability to provide care for sons Life expectancy of fathers Social development and social skills
Sam John	Jacob John, Jr. (JJ)	High School 16 – 17 years	Functional Independence Graduation from high school Employment opportunities Driving Higher Education

Tim and Edward were the fathers who had the youngest sons most recently diagnosed. In the first interview, Tim expressed significant concerns about his son's communication abilities. He worried that his son was deaf since he would not respond to verbal commands. Tim expressed his concerns about the future:

You wonder if your kid is going to be able to function in society. How is he going to develop? Is he going to be able to do the normal things that children do? ... I had a

lot of questions about how he could function in society. Stuff you think about when that happens. I just wanted him to speak.

When asked about his hopes and dreams for his son, Tim responded simply: "[I want Matthew] to be his [own] guy....independent, self-sufficient. That's my hope and dream."

In the final interview Tim expressed continuing concerns about Matthew's independence. He spoke of his concerns that his son be able to acquire skills of functional independence such as driving and how failure to do so would limit his independence in the future. While Tim continued to have these hopes and aspirations for his son, he was realistic about his son's communication and language difficulties and how those difficulties had connections to concerns for his son's future independence.

Edward had two sons with autism spectrum disorders, and was not only concerned about the future of his two sons, but also the pressures of time on preparing these boys with a basic education in skills such as reading and writing. At the beginning of the initial interviews, Edward's son Tommy, age five, also had major difficulties with communication skills. Edward explained:

The biggest hope is that they can function in society. It doesn't have to be at an enormously high level. Just enough to take care of themselves and enjoy life.... And that they have an education....There is a small window of time that we have to get so much education into them where they have basic reading functions, math skills, stuff like that.... And with Nathan, we haven't even started....My biggest fear is that Nathan is going to be 25 years old and he can't take care of himself and he can't function.

In the final interview, Edward began to differentiate concerns for his sons with a major focus still on Nathan, his youngest son with the most severe communication, social, and behavioral issues:

I am less worried about Tommy than Nathan. Tommy seems to [have difficulty mainly with] social skills [whereas] Nathan is under-developing. As far as Nathan's future, I feel like I am worried about him functioning within society and want him to be able to have a job and a family. You kind of dash those when you get the news [of a diagnosis of autism] at first. I think I am more hopeful now than I had been because I am finally seeing something. When you initially talked to me he hadn't said anything and he was going through terrible fits. Since we first talked, he would get mad and take off all his clothes. I worry about him emotionally adjusting to a world that he can't change and that won't remain constant...I worry about him finding that routine in the future. I am more hopeful because he is starting to talk, make sentences. He is also beginning to express his emotions. I always felt it was going to be muted with him or lessened about how much he could do. I want him to have some place in the world and that is what I worry about beyond myself and beyond me taking care of him.

Both Tim and Edward had concerns about their sons' futures that appeared to stem from the immediacy of ensuring their children had basic educational and communication skills. Their concerns seemed related to the severity of their sons' communication disabilities which heightened their concerns about independence.

Brad, the father of Joseph, age 10, and William, father of David, age 11, expressed concerns about the future related to their own life expectancies and inability to take care

and provide for their sons. Brad worried about how his son would be treated and how he would feel about himself:

I want him to be a confident young man. I don't even know if he knows he is different. I think he does. But I am not sure. I asked him one time. About two years ago, we were sitting in front of the TV and I asked him if he knew what autism is and he nodded his head yes. I asked him if he thought he was different. He said, "Yeah, I am different dad." I can't say with a hundred percent certainty that he understood what I was asking him. I get the sense he knows he is different. Long term, can he be self-sufficient? Joseph is fortunate. He has got intelligence to do anything. I don't know if he will be able to overcome the social and communication problems.

In the final interview, Brad expanded on his wife's and his own concerns about who would take care of his son in the event that they were no longer able to do so, and they had begun to prepare in this event:

My wife and I are starting to search out possible group homes when he gets older. In our head, we always hold that hope that he will graduate high school and find a job and live on his own. Find him a girl, the whole shebang. We also know there is a good chance, better chance; he will be living with us while we are around. Through our line of work, we are looking at those group homes, residential placements. We are starting to get things in line if that has to happen. We would like for him to have somewhere safe to live.

Not being around to take care of his son was a concern also held by William.

William was the oldest of all the fathers interviewed and had four grown children who had children of their own. He said that already he had had a longer life than other males in his

family. In addition to concerns related to his own life expectancy and being able to take care of his son, William worried about how his son, David, was seen by himself and others:

I worry what would happen to him if I wasn't around. What's going to happen when he grows up? That's one of the main reasons I quit chewing tobacco. Cause I want to be around.... [I worry about] what his life is going to be like. How are other people going to interact with him? I worry about how he is going to see himself in the world. [My wife] worries about how he is going to be taken care of. I know we both worry to some extent what is going to happen to him when we are gone. I am 53, she is 47. David is 10. Longevity runs in her family. I am the first member of my family to make 50 without having a heart attack.

While Brad and William both had concerns related to their sons' futures, their concerns appeared to have evolved beyond the issues of basic communication skills to issues related to their own life spans and their sons' self-concepts. Communication issues, while still important, did not appear to be the primary concerns of the fathers at this stage of their lives or their sons' development. This change may be related to the progress in their sons' development of communication and cognitive skills. Concerns were still evident about both boys' social development and social skills. As both boys progressed into middle school, their fathers indicated that their sons appeared to be more aware of their own social deficits. Additionally, both Brad and William have grown as fathers in their own knowledge, awareness, and acceptance of their sons' diagnoses and disabilities. Both fathers shared that they had accepted their sons' diagnoses, had increased their knowledge of the disability, and better understood their sons' social, emotional, and cognitive needs.

The fathers of the oldest boys were Sam and John. Sam was the father of Jacob, age 17 years, who had almost completed high school at the time of the first interview and had less severe communication, literacy, and learning issues than the other boys in the study. While he had observed his son's overall success with basic education, Sam continued to have concerns related to his son's future. Sam's concerns reflected worry about someone taking advantage of his son and Jacob's ability to be functionally independent:

[I have a concern about] how independently he will be able to live his life. Obviously if something were to happen to us, and thankfully we have made it this far with no tragedies, [I have concerns of] just how he would get along and where he would end up. How he would function as an adult. Could he be independent? I've tried to explain to him that a lot of people in the world will try to take advantage of you and you have to know the difference...He could have a hard time figuring [this] out... [I] figure he may have a little harder time. On the other hand, he has good intelligence. In his final interview, Sam noted that his son had graduated high school and was preparing to attend one of the local community colleges. Sam continued to have concerns about his son's functional independence and the possibility of being taken advantage of by others. He noted, however, that he believed his son was very close to being independent:

Any of us are vulnerable to getting deceived. For Jacob, if someone comes across as so earnest and whatever, he may not know all the ways to check up and may take it on face value that someone is being honest with him. I feel he would have a little more of a problem discerning things about a person wanting to take advantage of him. If he doesn't become independent, we will have to make arrangements for him to be

in some kind of group setting that is more of a long-term care facility. He is very close to being independent.

At the time of John's first interview, JJ was nearing age 16 and advancing in high school. John viewed his son as a high functioning child with an autism spectrum disorder. As a high school student, JJ was getting ready to get his driver's license. John expressed specific concerns about his son navigating from one location to another:

His future [is a concern]. Will he be able to do [things as others]? We are ready to face that now. He'll be 16 the 28th of this month...and he is hunting him something to drive. He's a good driver; he is responsible in there with us with him. He does have trouble navigating...That's our biggest concern, what will his life be like when he leaves our home?...You want to see your kids go out, be successful at whatever they do; whatever it is.

In the final interview, John added that his son would soon be a senior in high school. His concerns related to his son's overall happiness and ability to support his self financially. In addition, John provided some insight and information about post secondary education:

I want him to be happy. [I want him to be] successful as far as making ends meet and being able to financially support himself. [On a much closer level] he needs the education where he can pursue some things. Right now he is interested in [a career] in broadcasting. He has done some radio shows this summer while he has been out of school. [I want him] to get an education and have a good career and do what he enjoys.

All the fathers in this study had concerns about their sons' futures. Similarities existed across fathers related to the age levels and educational experiences of their sons. The

fathers whose sons were youngest and had the most severe communication needs had different concerns related to independence than the fathers whose sons were ready to exit high school, enter into postsecondary education, and attempt to have some level of functional independence. The fathers with sons in the middle grades had concerns more focused on the possibilities of long-term care and their sons' development of social skills.

### *Behavioral Impacts of the Son on Family Social Life*

Each of the fathers in this study expressed frustrations regarding negative behaviors exhibited by their sons with autism spectrum disorders and the impact these behaviors had on family and social relationships. Specific behaviors of concern included difficulties in bedtime routines, screaming, extreme defiance, and difficult and embarrassing behaviors, such as tantrums or crying, in public settings.

The fathers of the youngest boys gave the most detailed descriptions of their sons' difficult behaviors. Fathers of the children in the middle school age range shared concerns about behaviors and effects on their family's social relationships; however, they were more focused on experiences from the past rather than the present. The focus on experiences from the past suggests that as the boys progressed in age and increased communication skills, the intensity of behaviors lessened and fathers were better able to understand and cope with the behaviors. The fathers of the two oldest sons in high school were less focused on behavioral problems because of their sons' maturity levels. Edward, a father of the two youngest boys, explained:

[He] is fearless and he is smart and he knows how to manipulate you... He can do it and he tests [you]. There is not a cognitive problem [with manipulation] I don't believe. If anything, he is superior. He knows how to think. He is an opportunist

and if there is an objective that he wants, he will find a way to get that objective. For example, he knows that one time an egg was dropped and that egg was dropped in the kitchen and that attracted attention, then if there is something in the living room that he wants up on the shelf and he needs time to get it before mom and dad find him, he will go into the kitchen and drop an egg and wait for mom to go clean it and then he will go into the living room, set up stuff so he can climb up and have time to get it down and then run away with it back to his bedroom.

Tim, the father of Matthew, age six years, had similar experiences related to his son's verbal outbursts. Tim explained that the "lack of communication" with his son is one of the most difficult aspects in having a son with autism:

[It is difficult] when you don't know why he is yelling and screaming....When you try to get ready to go somewhere and he doesn't want to cooperate and you do what you are supposed to or you think you are supposed to and explain, use pictures, use preps. It just doesn't click and the battle, the difficulty of doing something or going somewhere or learning a new skill, or explaining to other people why the situation has happened. The screaming, or why it is difficult to go to a family reunion...and we went to the family reunion...and went in and we prepped and we prepped and worked and gave them information of what was going to happen and it just didn't click and he wasn't ready to go to this family reunion and he had a severe meltdown and [our] family was just being very helpful and they wanted to come up and 'Oh, how are you doing Matthew? Ah, poor guy' and pat him on the back, rub his head, and he just wasn't ready to do that, and so I left with Matthew, because I needed to get him out of that situation.

Both Edward and Tim gave detailed examples of the difficult experiences they have had with their sons. As the fathers of two of the youngest sons, they shared the most detailed accounts of negative behaviors.

William and Brad, fathers of the sons in middle school, shared similar experiences. A significant difference, however, was that they described their sons' behaviors through experiences in their pasts, whereas the fathers of the two youngest boys described the experiences as current and ongoing. As their sons progressed in age, parents and families learned methods to overcome and cope with their sons' behavioral difficulties and the effects upon their families. William explained:

It was difficult to go to the grocery store because [David] would have...fits and [my wife and I] did not know how to control them. Spanking didn't work...at all. [Once we began to learn about] the different techniques of motivating and manipulating, [and] sensory integration, once my wife and I started thinking differently, and realizing, let's do this and this. Once we learned the little tricks, life got better.

Similarly, Brad and his family learned about many of the experiences that caused problems for Joseph and the frustrations that accompanied them. Brad described his son as one who required "constant attention." He noted that days could seem very long due to some of his son's behavioral issues and the fact that his son seemed to have "non-stop energy." Brad claimed that the best purchase his family made was a trampoline for his son to use to burn off energy. He noted that the constant attention his son required was difficult on everyone in the family.

Brad said that one of the most difficult situations experienced with his son was getting healthcare services such as going to the dentist. Brad noted that Joseph's behaviors

interfered with dental care to the point that his son had to be completely sedated. In one of the first experiences of having his teeth cleaned, even accompanied by sedation, Joseph still had to be restrained. Brad added that any type of restraint or extreme noises would often cause negative behaviors and severe tantrums.

John and Sam, the fathers with the oldest sons, had very different behavioral concerns and experiences than the other fathers. Both of these fathers focused mainly on the behaviors related to their sons' compulsive natures and resistance to change. Both fathers noted, however, that when their sons were younger, their families experienced much more difficulty with behaviors. Sam commented that his family was "more conscious of taking [his son] places where [they] thought he might disrupt a situation." John added that when JJ was younger, his son would "[get] really frantic about stuff, where he would just freak out over things...if everything wasn't in order...For a few years, he was really acting out. We didn't go as much to places and do as much because we didn't know what he was going to do."

Interviews also revealed that the behaviors described by these fathers had at some time affected or continued to affect social relationships with others both within and outside of their families. All the fathers at the time of the study, had chosen to limit public interactions at some time in the past, or were very selective about the situations in which they placed themselves, their sons, and their immediate families. The most flexible of all the fathers within the study was John. His son, however, was one of the older children and had the least severe behaviors of all the boys in this study.

All the fathers revealed that they had experienced embarrassment or uncomfortable feelings in a public or social setting because of their sons' negative behaviors. Interviews

with five of the six fathers showed that the families functioned in a reserved capacity by selectively choosing whom they interacted with and by consciously narrowing social opportunities because of issues dealing with their sons' misbehaviors in public.

Edward, father of one of the sons in the early elementary age range, provided the following:

I have had some real unusual experiences taking him out in public. That's almost the hardest thing other than having them to deal with whatever problems you have on a daily basis is taking him out in public. That is when I feel the most different. You just feel like any parent when their kids act out or have bad behavior, you feel it is a reflection on yourself.

Edward's experiences also highlighted the limitations on social interaction. He described his experiences:

I don't think we go out as much. Kind of like with the embarrassment thing, you kind of feel like when you go out you try and anticipate everything so he doesn't show out in front of everybody. And we are not talking about terrible things. To everybody else that is looking, you have that natural embarrassment and understand why, but it still does not change the way you feel about it. Tommy is the same way just to give you an idea. He can do the same thing to you. I went to go pick out some shoes for him and he was with me. I go and pick out his shoes and try them on and they are fine. He thinks the shoes are ugly and they are not the same exact shoes that he is wearing. In his mind, the shoes that he's got on his feet are his shoes and they are only made for Tommy. Anything different does not do any good. So I bought him a pair of shoes that I know he likes and watches on TV, but I bring them up to the front

and he realizes I'm buying the shoes and he's going to have to wear them, and cuts a fit and screams "They are the ugliest shoes in the world! I hate them!" So you are carrying him out once again in that public area. We try [to go to restaurants] but my wife is more discouraged about it than I am. I still try. I still take them out by myself. My wife will do it if she has them all in a cart. She will go out and shop but ... being with them in a public place and they start showing out or whatever, that is when she won't tolerate it. She will leave or go somewhere. I think if I am by myself with all three of them, I think I can deal with them better.

When asked if his son had changed his family social life, Tim added:

Being frank, Matthew, with autism, has changed my social life....We don't go out too much. We don't go out to family gatherings as much. We don't go to concerts because of loud noises, or festivals....We used to go do other things with other people a lot; especially [my wife] and myself before kids. We had a very active social life and now we don't have the same circle of friends. Why is that? Is it because of having kids or having a child with autism? [I think it is] probably a little of both. Because a lot of people really don't reach out, and maybe we don't reach out because we are in a nice self-contained place. And we are in a safe place and so we don't venture out of our little group very much.

William commented about his social-life experiences:

We did not go out as a family. It was way too difficult to go to the grocery store because he would have these fits and we did not know how to control them. Spanking didn't work....So spanking, I tried that a couple of times with Nick. It didn't work at all. [Then] I started going through the TEACCH training and

learning...the different techniques of motivating and manipulating, [and] sensory integration. Once my wife and I started thinking differently, and realizing, let's do this and this, once we learned the little tricks, life got better. We could go out to a restaurant again. When we used to have the big get together at the holidays and stuff that was overstimulation. We hurt some of the other family member's feelings.

When we learned there were certain times, David can take this for so long, and we have got to pull back and go back to the house, go back to the hotel room or whatever, give him downtime, we did that.

Brad described how his son had changed his family's social life:

Everything we have to consider for every social event, we have to consider him. Anywhere from church to movies. He won't go to a movie theatre. Too loud. He won't wear ear plugs. That won't solve the problem. He won't keep them in. [The] number of friends we have has gone down...Our friendships outside [my wife and me] have lessened. I had some friends, one, in particular, was uncomfortable. He and his family were not comfortable. You could tell he sensed this (the autism) would rub off on his kids. I can recall his kids about the same age would copy some of Joseph's strange noises he would make. He would say, "No, don't do that. Don't talk like that. Talk like a regular boy." Over time, you see them less and less. Before you know it, you don't see them.

When asked about changes to family social life, Sam expressed that his son only had minor effects on this because of the natural tendency of his family to limit their social movements and that he and his family tended to be introverted regardless of his son's disability:

I am not that kind of person that has to go out and do a lot of things socially. I am content to hang out at home and be with the family. I don't have a need to be out too much socially. I enjoy it when I do it. My dad had to get out. He would get stir crazy if he had to stay home long.... We might have been more conscientious of [not] taking him places where we thought he might disrupt a situation. Once again, there didn't have to be that many instances because we didn't have any kind of social calendar.

John shared that his son's behaviors affected his family's social life for a few years when his son was younger. He explained that he and his family went to different places, but they limited some trips and going out in public due to his son's unpredictable behaviors.

The focus on behaviors as described by the fathers in this study was most intense with the fathers of the youngest sons due to their extreme behaviors. This was also related to the more limited amount of time the fathers of the younger sons had in understanding their sons' disabilities and behaviors. The familiarity and understanding of their children as well as the experiences of their sons in educational settings with the boys in middle and high school appeared to have helped these fathers understand their sons' behavior difficulties and strategies to cope.

#### *Experiences with Their Own Fathers*

When fathers in this study were asked to tell about their own childhood experiences with their fathers and how their experiences with their fathers affected their experiences with their sons, five of the six fathers had positive memories and experiences. These fathers described their fathers as being positive and influential in their lives. Only one father had negative perceptions of his relationship with his father and had been reared primarily by a

maternal grandfather. This father's perception of the relationship with his maternal grandfather was positive and in accord with the feelings and memories of the other fathers. Three of six fathers, Sam, Edward, and John, grew up in homes with a traditional nuclear family containing a mother and father in the home. Tim lost his father in his teenage years, with Brad being reared solely by his father after divorce, and William mainly by a maternal grandfather and grandmother. The following excerpts from interview transcripts describe these fathers' experiences and relationships with their own fathers.

Tim described his father in the following manner:

My dad was a really good dad. [He] really loved me. My dad died when I was 17. He was sick for three years...when he died of cancer. I will tell my older son stories about my dad at nighttime. I'll say well let me tell you a story about my dad and I didn't come up with one. It's been 24 years since he passed away. I am starting to forget things. He was a really good guy. He showed me how to hunt, showed me how to work on things... He was one of those guys that could fix anything... I know he really loved me because we hung out together a lot and we did things together. I don't remember a whole lot except for the time that we spent together. I try to do that with my boys and spend that time because that is what really matters is the time....Also my dad died when I was young so I know that a father can be taken away quickly or there was a long sickness that was very trying, so I'm trying to keep myself healthy. You know I am eight years away from when he passed away and my grandfather was 49 and his father was in his forties or fifties....That affects the relationship with my boys, in wanting to stay around a little longer or as long as God wants me to if I have a choice in that.

Unlike the other fathers interviewed, Tim lost his father as a teenager. Pivotal to Tim's memories and recollections of his father was the amount of time that they spent together and the love his father showed for him in coming to baseball games. Tim's view of his father's relationship with him as a son has transferred to the relationships that Tim has with both of his sons. In the final interviews with Tim, he described his relationship with his son as a "very loving caring relationship, [that was] very close knit." He also added that his own view of being a good father was to "take time to be there with your boys," much like his own father had taken time to be with him. Tim believed he was a good father like his own father was to him and emphasized the importance of spending time with his sons:

I love my boys and I want to spend time with them. It is not about staying over at work and making money to give them things. It is about taking those 15 minutes and to help teach them a little bit. When I come home, I want to spend time with them. That is my benchmark, litmus test. Be a positive role model.

Edward's father, unlike Tim, was still alive and involved in his life. In addition to his father, Edward also has siblings who were also involved in his day-to-day activities. Edward had the following thoughts about his father:

Dad was always [about] honor [and] family cohesion. That was always stressed by him and that you and your brothers are like fists. That's his analogy. We are like fists; united. That's how I grew up. He was always a consummate father, even when he couldn't be with us all the time. We are talking about a guy that worked from anywhere to 80 to 100 hours per week to support us...Just somebody that was dedicated to providing for his family. [He] would support us emotionally. He wasn't

a distant person. He was a loving, caring father. He would hug us. So we had a very loving, caring father who was extremely dedicated...He was not at a distance.

Edward, like his father, was also dedicated to providing for his family and spent a lot of time at work to support his family, especially when his boys were younger. His wife did not work outside of the home. Edward also was very much committed to the concept of family cohesion. He stated that he and his wife “have a commitment [and] both of [us] wonder if something were to happen to the other one, it would weaken our effectiveness.”

In the final interviews with Edward, he added that he considered himself a loving father and a caring father; however, he also felt like he often failed at fatherhood:

I always see how I could have done something better. Man I really screwed up that time. Those feelings may be normal. Early on, I think I was too oppositional in the beginning with Nathan. If I could have gone back, I would have done something better [with regards to his behaviors].

Brad was unique in that he was the only father who had been reared by a single father due to his mother and father getting a divorce and his father receiving custody of him and his sister. Because of this experience, Brad had a close bond with his father. Brad described his relationship with his father and family:

[Dad and I] are real close. [My] folks divorced when I was eleven. My dad kept me and my sister, which back then was really unusual. Not that that was that long ago. I think back in the 70s there was a given that you were going to go live with your mom when you got divorced. Mom just didn't have the financial means to do it. He was a great mom and dad. He was good at it. He cooked. He taught me...He was very big in being self-sufficient and he worked for the federal government. He was a

postmaster so he was a pretty structured guy. He is this person I look up to. When events happen in my life, other than [my wife], he is the one I call when I want to know what to do in a situation. I'm 42 now, but he is always dad. He is the person I still want to most impress, other than my wife. I want to make sure he is proud of me, that kind of thing. What got me about him was he was always levelheaded. I was always impressed about him and I tried to copy that...He is a good guy.

In the final interviews, Brad noted that he believed he was a good father and attempted to emulate the same characteristics that he admired in his father:

I try to do like [my father] did. I try to be there for my kids. I am patient with my kids. I try to be even-handed with discipline. I try to be fair with my kids. The biggest piece of it is being there. If you are not there you can't do any of it. I can have all the great ideas in the world. But if I am not there, it doesn't matter. I am more level tempered than my wife anyway. I am the peacemaker in the house. Smooth things over. Keeps things calm. My wife tells me in a joking way that I am a better dad than I am a husband. [This] is probably true.

William was also different from the other fathers in that his father, while still a part of his life, had abandoned him to be reared by maternal grandparents. William viewed his maternal grandfather as the major father figure in his life:

My mother's dad, who basically raised me, was very hugging and would say I love you. [He would] physically touch us. [He] act[ed] more like a father figure. [He was] good [and] he had morals. My dad was not a good man. My grandfather was there my entire life.

William also believed that he emulated many of the characteristics that he had observed in his grandfather, especially related to the aspect of being moral and making sacrifices for his children. In the final interviews, William commented that he believed he was a good father to his children:

I try hard and know what is important. Like my grandfather said and my mother. You can suffer anything for your children. I believe everybody should feel that way. That is why I quit chewing tobacco, quit drinking sodas a lot. [I wanted] to be healthier and be around longer... I have to in order to take care of him. I have questioned family members and friends [about this]. I feel I have changed [from when I was a young man]. One of the things they pointed out was [that I was] always a good man, morally upright... [I would] give [the] shirt off my back. Do anything for my children.

John also shared that he and his father had a positive relationship and that their relationship was more relaxed than typical father-son relationships. He expressed that he and his father participated in many activities together, both work and recreation. John described his relationship with his father:

We had a good relationship. A lot of my friends envied me and my dad because he was more laid back with me. At 16 me and him had went out and drank a couple of beers together. He knew I did it. Don't drink a whole lot. You get drunk, that's stupid. He was trying to teach me stuff like that. He played ball with me some when I was younger. Take me out and we would go out in the woods. We had a wood heater in the house with the other heat, the oil heat, and so we would go out in the

woods and cut wood and do stuff like that together. More work related stuff. We had a pretty good relationship.

John's relationship with his two sons also seemed to take on many of the characteristics of his own relationship with his father. In the final interviews, John commented that he believed that he was a good father to his sons and that it was important as a father "to give you the rules and discipline and be a friend to you, too." He added that, as a father, he wanted each of his sons "to know you can go to him and talk to him and listen to you and help you with problems."

Sam was reflective of his experiences with his father and seemed to have a strong admiration and respect for his father and the life he had lived:

My father was a hard worker and that kind of defined him in a sense that he did not have a lot of formal education from beyond HS. He went into the Navy when he was just barely out of high school and it was [during] World War II and he did that a couple of years. I am not sure how much college he got, but he got some... What I learned from him, I suppose, he believed in authority. He wasn't the strictest parent in terms of every detail of our lives. We knew he was in charge and there were things that he expected... My perspective to my father is he was good as in I knew he loved me. He didn't have to say it a lot. His actions spoke it. I knew he was providing for us and he worked hard. That in itself says he loved us because he's not negligent in his duties of providing for his family... He was a good member of the community and very giving to the community... [He was a] good, loving father.

Sam noted that he was not like his father in the aspect of being socially outgoing. Instead, he took greater pleasures in the deeper, philosophical discussions about life in general. Sam,

however, was like his father in that he believed in the role of authority and having clearly defined expectations for your children:

[In our family] I am the enforcer [of rules and discipline] and he lets me know he is not as pleased [with me] as he is with his mom. You know, I can deal with that. I just say you will know even more when you grow up later that discipline is out of love and I am not here to be your buddy right now while you are growing up. You can't be the buddy and authoritarian figure. That is kind of our dynamic in the family.

In my final interview, Sam commented that he believed he was a good father balancing out his view of discipline and love. He interacted with his sons in a similar manner to what he had garnered from his father. Sam stated, "I try to do a lot of his things. I emulate with my own children. I feel like the providing, showing love, being a disciplinarian, but being tender, combined at the right ratio [is what he did with me]."

Each of these fathers had a high degree of respect, admiration, and positive connections with their own fathers. The only exception was William, who had a similar positive male-to-male relationship with his maternal grandfather. The male-to-male bonds and relationships that existed between the fathers in this study and their own fathers appeared to have similar influences on the connections and dedications toward their own children and families.

Each of the fathers attempted to emulate something from their relationships with their own fathers, and their fathers had influenced how they viewed fatherhood and interacted with their sons. For Tim, who lost his father at a young age, the time that he spends with his children was important. For Edward, dedication and cohesion as a family were important aspects that he transferred from his experiences with his father. Brad, reared by his father,

valued the characteristics of being levelheaded and dedicated to his children and family. William valued the morality that he saw in his grandfather and the importance of making sacrifices for his children. John valued the aspects of friendship with his children much like the relaxed relationship he had with his own father and the openness of knowing that his children were able to come to him for help. Sam valued the role of the father with regard to being both loving and disciplinarian to his children, as he had seen in his own father.

#### *Involvement in Their Sons' Education*

All of the fathers interviewed in this study were involved in the education of their sons. Sam was the only father of the six participants who had lesser involvement in educational activities, deferring to his wife's expertise as a teacher. One commonality emerged from the interviews in that all the fathers shared in some capacity involvement in assisting with their sons' literacy-related activities. All the fathers noted the importance of assistance with activities such as completing homework, reading at night, reviewing spelling, and assisting with basic communication skills.

Tim, Edward, and Brad, the fathers of the youngest sons, were more focused on the specific skills related to learning to read than the fathers of the older sons. This involvement in their sons' educations was related to their concerns for their sons' futures, which primarily focused on improving communication skills. Tim and Edward, who had the two youngest sons with the most severe communication deficits, both took personal responsibility and involvement in the activities that occurred each day concerning school and reading. Tim said:

I am the baggy book guy. We read a baggy book every night and [review] sight words. It is my goal for him to understand what that book is about. He is a very good

reader. He knows his sight words... [My wife and I are regularly] meeting with teachers [and] working with this IEP team together.

Edward added that he took personal responsibility for basic literacy skills:

I think, number one, my responsibilities are to take care of them and provide for them, but getting them to respond to academics, and writing, and basic functions like writing and reading. I feel like that is my personal responsibility for both of them.

Brad was aware that difficulties in being able to read could limit his son, Joseph, in future activities:

[I] make sure he learns as much as he can, especially reading. I feel if he doesn't learn to read it limits him and what he can do. Math is fine and all but my focus now is on reading... [I] sit down and do his homework with him... [I] read to him at night.

William and John, while also involved with reading, spent more time with the formalities of what was occurring in the classroom and with homework. Both of these fathers noted in their interview responses that they were involved in IEP meetings and that both attended meetings with their wives. William commented:

[The] majority of the time I take him to school and talk with the teachers. I know everybody in the school and his class. I know his caretaker for afterschool that the Autism Society provides, and we discuss what he is doing. We keep in touch with the teacher... My wife and I are both equally involved [in my son's education... [We] both attend IEP meetings.

John commented:

For the longest time, in the earlier years, seventh, eighth grade, middle school, we had to do a lot [to help him with] his history. [We helped with] history, and science, and

those sorts of things. Some of it, he is like, "Daddy, I don't know what they are talking about." So [I would say], "Let's read it and then answer the questions." [I] usually [attend] all the IEP meetings. [My wife] makes them where I can go; so we usually both go.

Sam, while involved with his son's education through assistance with school-related projects, spelling words, and other similar activity was much less involved than the other fathers. Sam noted that his wife was the primary custodian of his son's education:

[My wife] keeps up more with what he is supposed to do...and is involved in what is going on. I will be more involved in seeing that he does his [school] work...Once in a while I will assist with a project or spelling words, but she is the primary overseer of the education. She primarily attends IEP meetings.

All the fathers revealed that their sons' educations were important and were involved in some level of educational activity or support with each of their sons. The father whose wife was a teacher had the least involvement. The involvement in their sons' educations parallels the concerns for the future especially with the fathers of the youngest sons. Just as the fathers of the younger sons of elementary age had concerns with communication and cognitive abilities, similarities also existed with the fathers with the youngest sons and the focus on basic literacy skills related to their involvement in their sons' educations.

#### *Differences in Parenting Their Sons versus Typically Developing Siblings*

Four of the six fathers within this study had younger children than their sons with autism spectrum disorders, and three of the six fathers within this study had children who were older. Fathers were asked if the experience of having a son with an autism spectrum disorder had affected their decisions to have other children. Five of the six fathers responded

that having a son with an autism spectrum disorder had not affected their decision to have other children. Brad was the only father who said that he and his wife were afraid to have other children. He stated that “we didn’t want to have another. Not that we don’t love [our son]...Then we decided, I think our main focus was to have [another child to] grow up [with him].”

Fathers were asked if they parented all of their children the same or differently and to explain their responses. Five of the six fathers indicated that differences existed. Edward, the father of two boys with autism spectrum disorders commented that he parented his two sons differently based on differences in their behaviors. The following excerpts from interview transcripts provided insights into the fathers' differences in expectations and parenting of their children:

Tim commented:

I try to parent the same, but the expectations may be a little different. I expect them to be loving and caring for other people... [My older son] has a very outgoing personality...His expectation to be caring is held up higher.

Edward commented:

There is a difference. I don't want to say tolerant, but I guess so, there are certain misbehaviors by Nathan that we just accept because it is part of it. Tommy doesn't really misbehave. I think that is the difference between Nathan and Tommy [is that] Tommy is more socially aware of when he has done something wrong. I think we are stricter with Tommy than we are with Nathan because I think we are a little more forgiving of his behaviors.

Brad commented:

Because [my son] came first, we did not know what a typically developing kid was like. It blows us away [with] some of the things she can do. [My daughter] learns language naturally. It just comes. You don't have to teach her a word fifteen times a day for a month for her to understand what a word means. She just [gets] it. She just spits out words that she has in her head. With [our son] it was never that way. Still not that way. Our expectations are for her to be high and that we make sure we are pushing her to do all she can do and we expect a lot from her.

William commented:

[There has] been a big difference between the girls and David. Were they all the same? They were different. [My oldest daughter] got more of the authoritarian [than my youngest daughter]. I was harder on her and let her get away with murder...I have told them, once I found out about [David's autism spectrum disorder], we have been discussing difficulties that [my daughters] have had in raising their children.

Sam commented:

[I parent my sons] a little differently maybe. Joseph requires more definitive rule type parenting, whereas, [my other son], gets some of that too, he is probably more open to listen to the explanation and understand it. I will explain things to Joseph. He will hear it and acknowledge it but he doesn't want to necessarily accept it, but he will. Intellectually he understands it. When I explain things to them it gets through more to [my other son] or he understands it better, especially the social type things...Sometimes Joseph is simpler in that he is a little more black and white.

Only John believed that he had parented in the same fashion both his son with an autism spectrum disorder and his son who was typically developing. He noted that it was easier at the time the study occurred to parent his older son with autism than his younger son who was typically developing. “[My younger son] is going through the middle school thing and he is going to be more apt to do stuff that any boy would do, so I have to be a little bit sterner with him. JJ, as of right now, has gotten a lot more mature.”

With the exception of John, all the fathers interviewed in this study had different expectations for their other children in their families. These differences resulted primarily from higher expectations related to social skills, positive behaviors, and higher cognitive abilities.

#### *Changing Views as Fathers*

Each of the fathers interviewed expressed a variety of responses on whether they had changed as fathers or changed specific beliefs about fatherhood because of their experiences of having sons with autism spectrum disorders. The following excerpts from interview transcripts share the fathers' perceptions of how they believe they have changed in their views related to fatherhood:

Tim commented:

I think my view as a father has really grown deeply. Very deeply, or what I see as very important...It is more heartfelt. It is more intense. Being the guy that needs to help bring my boys along has really intensified a bit...I doubt myself [sometimes as a father]. Am I able to do this? Am I going to be able to give him everything he wants? Needs? Self doubt about it. It is a struggle. Then I believe it has helped me to be the father I need to be for him. I always doubt myself. I have this self-doubt

about who I am as a father. With Matthew having autism, I have to work with him hard to give him what he needs.

Edward commented:

If I thought [being a father] would have required patience, it is even more so. Much more than I thought. I feel that people that have normal kids they have it easier. I think that certainly, as far as discipline and everything else, I had a little box from how I grew up, on how to approach it. I really had to change my viewpoint.

Brad commented:

It is far more difficult than I could have ever imagined. There were times that I didn't know if it was worth it. There were times I wish I was somebody else. There was never a time that I didn't want [my son with autism] to be there. There were times I just wanted him to be a regular kid. I had no idea that being a father could be so difficult. It just doesn't stop. It is all the time. I don't know that other fathers, regular fathers, feel the same way. I think other families, other fathers, probably get more relief than we get, than I get. We don't have much time for outside interest. It has just kind of taken over our lives. We got nothing else we can do, we got no choice...Our mother-in-law lives with us downstairs and the initial plan was she would be helping out with the kids. Well, she tried, but she can't. It is just too much. When [my son] has one of these meltdowns like we were talking about before, I [have] got to be there. He is not violent, but he is a big kid. I need to be there just in case he gets mad and throws something. Fatherhood with [my son] is rewarding. The positive side to that is when he is successful; I know that we have really accomplished something.

William commented:

I feel more responsible [as a father]. I think I wanted to be around a lot more for my [son than I was for my other children]. I know that before we found out he was autistic, I felt responsible [for him being autistic]. It was probably my fault ...I am more aware of other people's views, where in the past there was I understood the world and that was the way it was. I am a lot more aware that everybody has the right to think of things in their own way.

John commented:

I guess I have gotten a little more like my dad now. Instead of [being] as strict as I was, I am more lenient... I know [my sons] are going to do things and I don't want them to not be able to say, 'Look dad, I messed up, I did this.' I don't want to lose communication with them and this is not really because of [my son with autism], but both of them...I think [my experiences of having a son with autism] is where I became more loving as far as hugging because [he] liked [to be hugged. Being hugged] would calm him down. You could hug him and I hug [my other son] too. I say, 'I love you, I know something is wrong, let's calm down, let's talk about it.'

Sam commented:

Since [my son with autism] was my first child and I didn't know any different, I guess I learned more about being a father to a normal child when my second son came along...I think I felt like [my life] was fairly normal in terms of a lot of our experiences [growing up]. I have wondered if [my son with autism] was a normal teenager with normal teenage problems, I would have [had] a whole different experience that I have been through that were equally stressful, but just different.

The fathers in this study experienced various changes by having a son with an autism spectrum disorder. The changes in their views on fatherhood were a result of their own individual experiences. Changes expressed by these fathers included feelings of personal growth, development of patience, becoming more tolerant, understanding challenges, and becoming more responsible. These fathers appeared to have difficulty in reflecting on how they have changed because their experiences with their sons were also constantly changing.

### Summary of Findings

The purpose of this study was to expand on the research of Long (2005) and address the gap in the research literature related to the role of fathers of children with autism spectrum disorders, the intimate relationships fathers experience with their sons who are diagnosed with autism spectrum disorders, and changes in their perceptions of fatherhood. Two questions explored in this research included: (a) What are the experiences among fathers of sons with autism spectrum disorders? and, (b) How do fathers' perceptions of fatherhood change through the experience of parenting a son with an autism spectrum disorder?

With regard to the first question: What are the experiences among fathers of sons with autism spectrum disorders? the six fathers, who served as participants in this study, had myriad experiences with their sons. This was in part due to the differing ages of their sons, the differences in diagnoses of each of the sons under the autism spectrum, and the specific issues each son had with communication, social skills, and behaviors. While each of the fathers had positive relationships with their sons and showed serious commitments to seeing their sons demonstrate success in spite of their disability. All the fathers shared their individual stories of the difficulties, work, stresses, and realities of having a child with a

disability. In spite of these difficulties and disabilities, each of these fathers was able to set realistic expectations for his son and was diligent in finding what worked to help him be successful.

Aside from the fathers' individual stories about their experiences, six major themes were identified. These themes include: 1) concerns for their sons' future; 2) behavioral impacts of the son on family social life; 3) experiences with their own fathers; 4) involvement in their sons' education; 5) differences in parenting their sons versus typically developing siblings, and 6) changing views as fathers. The first five themes provide information on the experiences of fathers of sons with autism spectrum disorders. The final theme, changing views as fathers, provides information on how the fathers perceived they have changed as fathers as a result of having sons with an autism spectrum disorder.

With the theme of concerns for their sons' future, all the fathers had concerns for their sons' futures with specific regard to their abilities to be independent as adults and how their sons would be taken care of when they as parents were no longer able to or around to take care of them. The intensity of these concerns appeared to be much greater with the fathers of the sons in the elementary and middle school age ranges due to greater issues with communication skills, cognitive abilities, and social issues. The fathers of the two oldest sons in the high school age range had concerns but were more focused on future concerns surrounding functional independence.

With the theme of behavioral impacts of the son on family social life, all of the fathers expressed frustrations regarding the negative behaviors of their sons and the impact of behaviors on their family social life, both past and present. The fathers of the sons in the elementary and middle school age ranges identified the greatest concerns related to behaviors

and the impact of these behaviors on their families. Intensities of behaviors appeared to lessen as the sons increased in age. This may have been attributed to the increasing maturity levels of the older sons and the abilities of their fathers and families to cope with behaviors and understand their sons' disorders. In addition, fathers explained that their sons' behaviors affected or continued to affect social relationships with others outside of their families or in family-type situations and had forced them to be selective in limiting public interactions outside of the their homes.

With the theme of experiences with their own fathers, the fathers had experienced positive relationships with their own fathers or father figures during their childhood experiences. Each father also viewed their fathers or father figures as having been good fathers for whom they had high degrees of respect and admiration. Each of the fathers in also attempted to emulate characteristics or actions from their own fathers with how they viewed themselves as fathers and how they interacted with their sons. The positive relationships between the fathers and sons seemed to correlate with the positive perceptions and relationships that each of the fathers had with their own fathers.

With the theme of involvement in their sons' education, all the fathers were involved in their sons' education. All the fathers noted that they assisted with activities such as reading and homework with their sons. The three fathers with the youngest sons had a greater focus on their sons learning to read and the development of literacy skills. This was most likely due to the severity of communication difficulties and cognitive difficulties experienced by their sons.

With the theme of differences in parenting their sons versus typically developing siblings, all the fathers had children other than their sons. Five of the six fathers shared that

they believed they parented their sons differently than their other children. These fathers believed they had higher expectations related to social skills, behaviors, and cognitive abilities for their typically developing children.

The fathers responded in various ways with regard to the second research question, “How do fathers’ perceptions of fatherhood change through the experience of parenting a son with an autism spectrum disorder.” Changes expressed by these fathers included feelings of personal growth, development of patience, becoming more tolerant, understanding challenges, and becoming more responsible as a parent.

## CHAPTER 5

### DISCUSSION

The purpose of this study was to expand on the research of Long (2005) and address the gap in the research literature related to the role of fathers of children with autism spectrum disorders, the intimate relationships fathers experience with their sons who are diagnosed with autism spectrum disorders, and changes in their perceptions of fatherhood. Two questions explored in this research included: (a) What are the experiences among fathers of sons with autism spectrum disorders? and, (b) How do fathers' perceptions of fatherhood change through the experience of parenting a son with an autism spectrum disorder? This study adds to previous research conducted by Long (2005), in which four fathers of sons with autism were interviewed to determine their experiences of having a son with autism. Table 5 identifies and summarizes the themes found in Long's study. Table 6 identifies the commonalities between Long's study and this study and additional significant findings from this study.

Six major themes were identified from the sets of interviews. Participants for this study were all fathers of sons diagnosed with an autism spectrum disorder. The six themes identified included: 1) concerns for their sons' future; 2) behavioral impacts of the son on family social life; 3) experiences with their own fathers; 4) involvement in their sons' education; 5) differences in parenting their sons versus typically developing siblings, and 6) changing views as fathers.

Table 5

*Themes from Long (2005)*

<b>Themes Identified from Long</b>	Summary of Themes from Long
<b>Concern for the Future</b>	Fathers had concern for future with ability of sons to provide for themselves economically and develop socially and emotionally.
<b>The Experience of Stress</b>	Fathers experienced stress with their inability to manage their sons' behaviors in social situations. Other areas of stress described by fathers included financial, marital, physical, and social factors.
<b>Fathers' Attitudes and Sensitivity</b>	Fathers expressed attitudes of being sensitive and caring toward sons regarding autism.
<b>Identifying Similarities</b>	Fathers identified similarities in themselves and characteristics as possessed by their sons with autism. Similarities identified by fathers focused on areas of deficits such as experiencing anxiety in new situations, difficulty in unfamiliar surroundings, sensory issues, and concerns with not making eye contact with others.
<b>Loss and Athletics</b>	Fathers expressed feelings of loss regarding athletic involvement with their sons with autism.
<b>Talking to Other Fathers</b>	Fathers were involved in support groups or organizations that advocated for individuals diagnosed with autism.
<b>Advice for Other Fathers</b>	Fathers encouraged other fathers with sons with autism to become involved in every aspect of their children's lives, including learning about autism and the educational needs of their children.

Table 6

*Comparison of Long (2005) Study with Additional Significant Findings from Current Study*

<b>Commonalities Between Long (2005) Study and Current Study</b>	Significant Findings from Current Study
<b>Fathers in both studies expressed concerns regarding their sons' futures. General concerns focused on sons having the ability to provide for themselves financially and attain economic independence. Fathers expressed concerns related to social and emotional development.</b>	Concerns for the future intensified with the fathers of the sons in the elementary and middle school age ranges due to greater issues with communication skills, cognitive abilities, and social issues.
<b>Fathers in Long (2005) experienced stress with their inabilities to manage their sons' behaviors in social situations and stress associate with social factors.</b>	Intensities of behaviors appeared to lessen as the sons in this study progressed in age.
<b>Fathers in current study expressed frustrations regarding the negative behaviors of their sons and the impact of these behaviors on their family social life</b>	Fathers experienced positive relationships with their own fathers or father figures during their childhood experiences. Fathers attempted to emulate characteristics or actions from their own fathers with how they viewed themselves as fathers and how they interacted with their sons.
<b>Fathers involved in the educational needs of their children.</b>	Five of the six fathers believed they parented their sons with an autism spectrum disorder differently than their other children. Fathers had higher expectations related to social skills, behaviors, and cognitive abilities for their other children.
	Fathers expressed a variety of changes including feelings of personal growth, development of patience, becoming more tolerant, understanding challenges, and becoming more responsible as a parent.

### Concerns for Their Sons' Future

The fathers' concerns for their sons' futures were consistent with the findings in the research conducted by Long (2005). Fathers in Long's study and in the current study had concerns about their sons' futures and concerns for their sons being able to provide for themselves economically and achieve financial independence. In addition, fathers in Long's study expressed concerns about the social and emotional development of their sons. In the current study, this was a concern expressed by fathers of sons in the middle school age range.

In addition, concerns for their sons' futures in this study were consistent with the literature regarding parental reactions of having a child with a disability. All of these fathers had concerns about their sons' abilities to live independently and concerns about how their sons would be taken care of when they were no longer able to do so. Central to these concerns were fears and worries associated with quality of life, independence, and the changes that arise related to the extension of a child's dependence on parents beyond what is typical (Featherstone, 1980, Rasmussen, 2000).

Williams and Wright (2004) noted that, "when a child is diagnosed with [autism], parents experience not only feelings of sadness and loss, but a range of fears for the future which replace the hopes and expectations that they may have had. These are difficult processes. Families may have to realign their aspirations for their child, and keep the future in mind as their child develops ( p. 35)." The six fathers in the current study shared a common concern for their children's futures across the ages of their sons. The changes in concerns appeared to correlate with the communication needs and abilities of the sons, the level of education, changes in behaviors, and the success of the sons, as they grew older and progressed toward success in school and possible independence.

The fathers' concerns for the future in this study were also consistent with Gray (2003); fathers in his research reported considerable concerns with regard to their children's future. Gray reports that fathers may have perceived the helping of their child with autism to reach some level of economic independence to be consistent with their role as a father. The desire to help their sons reach levels of economic independence was more evident with the fathers of the older sons in the high school age range.

The intensity of concerns appeared to be much greater with the fathers of the sons in the elementary and middle school age ranges due to greater issues with communication skills, cognitive abilities, and social issues. This is consistent with previous longitudinal research conducted by Gray (2002). Extending earlier research (Gray, 1994), Gray (2002) found that the difficulties associated with communication were less frequently cited as a problem for parents. Gray (2002) noted that this change may have been attributed to improvements in abilities or parental improvements in communicating with their children. In this same study, Gray also noted that the anxiety levels of parents related to their child's future had significantly increased as many of the participants children had failed to attain a full range of living skills originally envisioned. An important conclusion that emerged from Gray (2002) was that most of the families in his longitudinal study had experienced improvement and favorable outcomes with their children with autism. While this study does not focus on changes over time, it is plausible to see progression in communications skills across age ranges. In addition, the fathers in this study, particularly those with sons in the middle and high school age ranges, appeared to experience similar improvements in their sons' abilities with regard to abilities and their fathers' improvements in communicating and understanding their sons' disorders.

### Behavioral Impacts of the Son on Family Social Life

The concerns surrounding behavior issues of the sons in this study were similar with the findings in the research conducted by Long (2005). Long noted that the fathers in her study experienced stress with their inability to manage their sons' behaviors in social situations. The fathers in this study also expressed frustrations regarding the negative behaviors of their sons and the impact of these behaviors on their family social life. A difference in the current study from Long was the observation that the intensities of behaviors appeared to lessen as the sons progressed in age. This could be accounted for because Long's study only included fathers with sons from age 3-5 years, whereas the current study included fathers with sons that ranged from age 5-17 years.

The experience of stress and behavioral issues as found in both Long and the current study were consistent with the literature on parenting children with autism spectrum disorders. A review of the literature is very clear that the behavioral difficulties of children with an autism spectrum disorder are a key component related to the increased stress in their parents (Brobst et al., 2009; Bromley et al., 2004; Davis & Carter, 2008; Herring et al., 2006; Kasari & Sigman, 1997; Lecavalier et al., 2006; Szatmari & Archer, 1994). Marcus et al. (2005) identified multiple stressors associated with having a child with an autism spectrum disorder, including disruptive and embarrassing public behaviors as a major cause of stress. Likewise, in a study on parenting stress and child behavior problems, Dumas et al. (1991) recognized that parents of children with autism and behavior disorders experienced significantly higher levels of parenting stress than parents of children with Down syndrome or with normal development.

In other research conducted on quality of life and parental concerns as described in the literature, Lee et al. (2008) concluded that families of children with autism reported greater problems with childcare issues, lesser participation in activities, and lesser involvement in community services. This was attributed to the difficulties that parents faced in separating a child with an autism spectrum disorder from the home environment and consistent with the fathers in the current study, who have chosen to limit social interactions with others or have had their family social life curtailed due to their sons' disruptive behaviors. Gray (1994) identified some of the most difficult problems encountered by parents of children with autism to be inappropriate and embarrassing public behavior, disruption in the home, violence and aggression, and obsessions with eating. Interviews conducted with the six fathers in the current research revealed similar concerns with behaviors and was consistent with Lee et al. (2008) and Gray (1994). Moreover, in a ten-year longitudinal study, Gray (2002) noted continued issues with socialization and social rejection as a result of their child's behaviors.

#### Experiences with Their Own Fathers

The information provided by the fathers in this study regarding their experiences with their own fathers was not addressed in the study conducted by Long (2005) and is a unique. The fathers participating in the current study had strong admiration and connections to their own fathers or father figures. Having a positive father figure correlates with other research not addressed in the previous review of the literature. Other research, however, such as Lamb and Tamis-Lamonda (2004), noted that the amount of time that fathers and children spend together is probably less important than what is done with the time spent together. In addition, fathers have influence over their children directly through their behaviors, attitudes,

and messages conveyed to children. The motivation and goals of many men, as well as their actions, are dependent on the recollections of their own childhood experiences and the choice of either compensating for their father's deficiencies or attempting to emulate those experiences (Lamb and Tamis-Lamonda, 2004).

Other research on the relationships between fathers and sons by Yablonsky (2000), noted that many forces within a man's life could determine a particular parenting style. One of the most significant influences is the impression left on a son by his father. Like the fathers in Lamb and Tamis-Lamonda (2004) and Yablonsky, the fathers in the current study have attempted to model and emulate the positive experiences that they had growing up. Each father seemed to feel that their own fathers had a deep loyalty to their children and family. Even the father reared primarily by his maternal grandfather attempted to emulate the same type of relationship with his son that he had had with his grandfather. In addition to the relationships with their sons, there also seemed to be a strong belief in family and unity.

The fathers in this study were all married. In many families with children with autism, divorce can be a common occurrence (Bolman and Burns, 2006). The strong belief in family and the positive experiences they have had with their own families may be one plausible explanation for their intact marriages. Another plausible explanation as Bolman and Burns (2006) noted in a presentation to the Autism Society of America's National Conference on Autism Spectrum Disorders in 2006, is the importance of not allowing role divisions between mothers and fathers to occur and for both parents to have strong understandings about their child's autism and shared interests around their child. Bolman and Burns stated:

On the whole, moms begin to become the family autism expert. Although this is a good thing, it's not an altogether good thing, since some moms go off in the direction of being "super-moms" and some dads opt out and work extra hard to support the moms and the family, and the stage is set for two good people to head off in different life directions. There is no question that this role division is effective for a few years, but one of the things that keep marriages together is deeply shared interests. (pp. 1-2)

The fathers in the current research appeared to fit Bolman and Burns' (2006) description in that they were also very involved with their wives and the understanding of their sons' autism spectrum disorders. Coupled with the strong family beliefs they possessed and the closing of the knowledge chasm as described by Bolman and Burns (2006), this provides additional insights into how their family structures and marriages may have stayed intact.

#### Involvement in Their Sons' Education

Long (2005) noted that the fathers in her study encouraged other fathers with sons with autism to become involved in every aspect of their children's lives, including learning about autism and the educational needs of their children. The research conducted by Long, however, did not focus or provide any information related to the degree or means that her fathers were involved in their sons' education. All the fathers in the current research were involved in the education of their sons. Fathers attended IEP meetings or had attended such meetings in the past and assisted with school-related activities and assignments. Only one father interviewed from the six participants had taken a secondary role in the educational issues related to his son, mostly due to his wife's role as an educator. All of the fathers were not only involved in their children's educations but also played very active roles in home activities. These fathers participated with their wives in the educational activities such as

IEP meetings. The fathers within the current study, except one, gave no indication of interest or involvement in any support group activities for fathers of children with autism. The fathers, however, explained that they had attended meetings through organizations such as TEACCH or school activities with their wives to receive information related to autism spectrum disorders and that these types of meeting were related mainly to their child's educational needs and services. The fathers in Long's study, however, did note that they were involved in support groups or organizations that advocated for individuals diagnosed with autism.

While the fathers in Long's study showed support for the importance of their sons' education, the fathers in the current study provided much detail and information about the importance and type of involvement. The findings within the current study related to educational involvement were not specifically addressed in the review of the literature. Turbiville and Marquis (2001) compared fathers of children with and without disabilities in early education programs and found father participation in educational activities was strongly linked to the activities in which fathers could participate with their wives or partners. Activities in which fathers were least likely to participate were those that were offered to men only (i.e., informational meetings for men, men's support groups).

Nord (1998) also noted that fathers in two-parent families were much less likely than mothers in two-parent families to be involved with their children's schooling and fathers' involvement, like mothers, decreased with children's ages. The fathers in the current study, however, contradicted these findings. All the fathers were involved in their sons' schooling regardless of age. Nord (1998) also noted that parents who were involved in their children's schools were more likely to be involved at home and that in two-parent families, the

strongest influence relative to father's involvement was the mothers' involvement. The fathers in the current research actively participated with their wives and their children at school and at home. These findings correlated with previous research by Turbiville and Marquis (2001) and Nord (1998) that reported fathers who participated with their wives in two-parent families were also involved in the educational activities of their sons at home.

#### Differences in Parenting Their Sons versus Typically Developing Siblings

Each of the fathers in the current study had children other than their sons with an autism spectrum disorder. Likewise, each of the fathers that participated in the study conducted by Long (2005) had children other than their sons with autism. The study conducted by Long, however, did not address any differences in parenting siblings of their sons with autism. Moreover, the literature surrounding siblings of children with autism was not directly addressed due to the focus of this study being on the experiences relating to parents of children with autism spectrum disorders, particularly fathers. Gold (1990), however, did recommend that additional research be conducted on gender differences in family members within families having children with autism with specific research focusing on the unique experiences of fathers and brothers. Through personal email communication (J. A. Isenhour, personal communication, March 13, 2010) with Gold requesting knowledge of any responses to the recommendations from her study, a reply (N. Gold, personal communication, March 15, 2010) was received that Gold was unaware of any research regarding the unique experiences of fathers and brothers regarding gender roles.

With regard to family dynamics, the Autism Society of America has provided information on families of children with autism noting that the demands of having a child with autism may often leave parents with less time for the needs of other children within the

family (Harris, 2008). In addition, siblings of children with autism are vulnerable to potential sources of stress resulting from issues such as embarrassment around their peers; jealousy regarding the amounts of time parents spend with autistic siblings; communication frustrations with their autistic sibling; receipt of aggressive behaviors; concern regarding parental stress or grief; making up for family deficits; and, concerns over future caregiver issues (Harris, 2008).

Reid (1999) noted the following stresses created in a family with an autistic child and the effects on other children:

Having an autistic child can be likened to having a cuckoo in the nest: the autistic child takes more and more of the family resources, but is unable to give anything much back. Other siblings get kicked out of the *nest* of parental space and, recognizing that their parents are already overtaxed, frequently become pseudo-good assistant parents. Parents' relationships frequently suffer; with each other, with their other children and the wider community. (pp. 66-67)

The fathers in this study did not indicate that relationships with their other children had suffered as a result of having sons with autism spectrum disorders. Expectations, however, for their other children were held to higher standards possibly helping to alleviate family stressors and to help in managing and coping with family stressors and deficits created by their autistic brothers.

#### Changing Views as Fathers

The research conducted by Long (2005) did not address changing perceptions fathers experience as a result of having a son with and autism spectrum disorder. The changing views expressed by the fathers in this study seemed to reflect feelings that they had evolved

in some manner as a father. In discussing the life phases of the interactions between fathers and sons, Yablonsky (2000) identified the closest emotional relationship that exists between fathers and their sons generally takes place between the ages of birth and age twelve years. This period of development is identified as ego blending, Yablonsky noted that fathers' macho attitudes are put aside and men begin to reveal their deeper emotions. In addition, Yablonsky observed:

Fathers who relate to the physical and emotional needs of their young sons on a daily basis tend automatically to merge with the sons' egos and feel with them on a deep emotional level. His view of the world must become more compassionate and loving as he consciously observes and participates in the development of his son's self. The process is one of the most profound growth experiences any man can have (pp. 90-91).

The fathers in this study gave evidence that they had experienced the father-son relationship in much the same way as described by Yablonsky (2000). Following initial reactions of denial, shock and grief, these men had taken great efforts to understand their sons' autism spectrum disorders and, as well, had immersed themselves deeply into the social and emotional aspects of their sons' lives. As a result, they have changed in how they view the world through their sons' disability and uniqueness. The changing views on fatherhood that these men have shared were in essence the changing experiences of their sons. It should also be noted that the processes that parents undergo in coming to terms with having a child with a severe disability are complex journeys that span the entire life of a parent's existence. As the sons grew and progressed from the experiences described by the fathers in this study, so have the fathers grown and progressed. They were so deeply connected to the social and

emotional aspects of their sons' lives and successes, as we see the changes in their sons, we also see the changing views they experienced.

#### Limitations of the Research

The limitations in my research primarily have to do with my role as a doctoral candidate conducting phenomenological research for the first time. While I was skilled at connecting with these fathers and forming a trusting relationship with them, which enabled them to share their experiences with me, at times I was unprepared for the emotional content of their sharing. Also, in conducting member checks, I asked participants to review perhaps more content than necessary which may have been overwhelming to them. Were I to conduct this study again, I would take more time with this process to review sections of transcripts over time and revisit/discuss possible themes to a greater depth with participants and committee members. Additionally, some of my follow up contacts were made over the phone, and face to face contacts may have extended or deepened conversations with participants in new ways.

Also, while my purposive sample of six fathers with sons of different ages and abilities allowed for in depth sharing and analysis of their experiences (a strength of phenomenological research), results are not intended to generalize to all fathers of sons with autism in the United States. For example, my participants have sons with mild to moderate autism spectrum disorders and may not be representative of families with sons with the most severe autistic disorders; nor are they representative of families with fewer economic resources, or perhaps from different ethnic and cultural backgrounds.

### Suggestions for Future Research

While this study provided additional insight into the experience of fathering a son with an autism spectrum disorder, further research is needed to broaden understandings related to the experiences and perceptions of fathers of sons with autism spectrum disorders. This study included only participants married to the mothers of their sons with mild to moderate autism spectrum disorders and included fathers in families with at least two children, including the son with the disorder. Future research needs to be implemented to broaden the understanding of the experiences and perceptions of fathers in a variety of contexts. Suggestions for other research should include exploring the experiences and perceptions of single fathers as compared to married fathers as well as the experiences and perceptions of fathers of sons with severe communication and behavioral issues. The fathers in this study were all homogeneous with regard to comparable socioeconomic status, such as identification of career fields, and ethnicity. Additional research should explore the experiences and perceptions of fathers across different levels of socioeconomic status and diversity based on ethnicity.

The fathers in this study, while continuing to deal with difficulties and frustrations surrounding their sons' autism spectrum disorders, have continued to stay married and cope with their sons' disabilities through a strong family dynamic, and presumably by finding shared rituals and ways to engage with their growing sons. Suggestions for other research should include exploring understanding how to help men cope with having a son with an autism spectrum disorder and the strategies that can be employed to help families with children with autism spectrum disorders to maintain healthy marriages and relationships. Specific focus should be directed toward understanding the intricate dynamics within

families that promote success and understanding related to coping through spirituality and religion.

Additional research should also examine the effectiveness of schools and policy makers in understanding the needs of parents of children with autism spectrum disorders and their level of responsiveness to creating policies that are supporting the needs of families. As the enigma of autism continues to grow, it is important for educators to understand these disorders and help parents and families find success within the educational setting.

#### Implications for School Leaders and Administrators

This study stemmed from personal experiences as an elementary school principal through attempts to work closely with parents of the children in a self-contained class serving students with autism spectrum disorders. A goal in the early stages of this experience was to simply develop a better understanding of the issues related to educating and living with a child with autism. From this research and personal experiences in attempting to find greater insight into the families of children with autism, particularly that of fathers, an implication for administrators is to realize that their current understandings and beliefs about children with disabilities and their families may not be accurate. It is important as an administrator, and especially as a principal, to carefully examine the lens we look through with regards to children with disabilities and their families. Too often, administrators can bring preconceived notions, misunderstandings, and misinformation to bear on their decisions in working with families of children with special needs.

An additional implication for administrators is the responsibility of staying informed and sharing knowledge and understanding with teachers, counselors, fellow administrators, and students about autism spectrum disorders. As the numbers of students with autism

spectrum disorders continue to increase in schools, it is important school administrators at all levels be proactive in understanding the spectrum of disorders and how better to serve students and families.

Personally, through this research, I have deepened my own knowledge about autism spectrum disorders and the experiences and insights related to being a father of a child with special needs. Most importantly, the fathers in this study have taught me about the importance of listening to the stories of others and taking time to understand the frustrations, joys, and everyday experiences that our parents have with their children. It is important that school administrators also take adequate time to listen to the stories of parents, especially those with children who have special needs or situations that may cause stresses to occur within the family dynamic.

Throughout the process of completing this dissertation and working with families and students who have an autism spectrum disorder, I have been able to develop deeper compassion and empathy for parents. This study has helped me to better understand the different disorders under the autism spectrum as well as gain greater insight into the individual lives of parents that have a child with a disability. Through this process, I believe I have become a better communicator with parents of children with autism spectrum disorders as well as parents in general. I constantly attempt to listen to parent concerns and develop a deeper rapport and trust between the school and with parents and families. In addition, I have used the knowledge from this research to educate my teacher colleagues relative to topics of autism spectrum disorders and work with families of children with disabilities to develop positive relationships. I believe, as educators, we must mold our practice of communication with others to become similar to the idea from the Story Corps

Project, where everyday individuals are interviewed by those who know them with the purpose of “encouraging us to connect despite endless temptations to detach and disengage” (4, Isay, 2008). The implication we must hold in attempting to work with and understand the parents and families of children with autism spectrum disorders and other disabilities, as well as all who enter our schools, is:

That our stories – the stories of everyday people – are as interesting and important as the celebrity stories we’re bombarded with by the media every minute of the day.

That if we take the time to listen, we’ll find wisdom, wonder, and poetry in the loves and stories of the people all around us. That we all want to know our lives have mattered and we won’t ever be forgotten. That listening is an act of love. (Isay, 2008, p. 4)

## BIBLIOGRAPHY

- Adesida, O., & Foreman, D. (1999). A support group for parents of children with hyperkinetic disorder: An empowerment model. *Clinical Child Psychology & Psychiatry, 4*(4), 567.
- Altieri, M., & Kluge, S. (2009). Family Functioning and Coping Behaviors in Parents of Children with Autism. *Journal of Child & Family Studies, 18*(1), 83-92.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC: American Psychiatric Association.
- Anderson, J.M., & Elfert, H. (1989). Managing chronic illness in the family: Women as caretakers. *Journal of Advanced Nursing, 14*(9), 735-743.
- Armstrong, D. D. (2002). Neuropathology of Rett syndrome. *Mental Retardation and Developmental Disabilities, 8*, 72-76.
- Baker, H. (2002, April). A comparison study of autism spectrum disorder referrals 1997 and 1989. *Journal of Autism & Developmental Disorders, 32*(2), 121-125.
- Baker, B., Blacher, J., & Olsson, M. (2005). Preschool children with and without developmental delay: behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research, 49*(8), 575-590.
- Baker, B., McIntyre, L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research, 47*(4/5), 217-230.

- Baker-Ericzén, M., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research & Practice for Persons with Severe Disabilities*, 30(4), 194-204.
- Barnhill, G. P. (2001). What is asperger syndrome? *Intervention in School and Clinic*, 36, 259-265.
- Baxter, C., Cummins, R., & Yiolitis, L. (2000). Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual & Developmental Disability*, 25(2), 105-118.
- Beckman, P. (1991). Comparison of mothers and fathers' perceptions of the effect of young children with and without disabilities. *American Journal on Mental Retardation*, 95(5), 585-595.
- Bertrand, J., Mars, A., Boyle, C., Bove, F., Yeargin-Allsopp, M., & Decoufle, P. (2001, November). Prevalence of autism in a United States population: The Brick Township, New Jersey, investigation. *Pediatrics*, 108(5), 1155-1161.
- Blacher, J., & Baker, B. (2002). Families and mental retardation: A collection of notable AAMR journal articles across the 20th century. *American Association on Intellectual and Developmental Disabilities*. Washington, D.C.
- Blackurn, C., & Read, J. (2005). Using the Internet? The experiences of parents of disabled children. *Child: Care, Health & Development*, 31(5), 507-515.
- Blair, P., Block, K., Chambliss, C., Hobbs, N., & Urgarte, A. (1996). *Parental Perceptions of the Lifestyle Changes Associated with having and Autistic Child*. Retrieved from Educational Resources Information Center (ERIC).

- Blaxill, M. F. (2004) What's going on? The question of time trends in autism. *Public Health Reports, 119*, 536-551.
- Bolman, W. M. , & Burns, J. A. (2006). #1940- the autistic family life cycle: family stress and divorce. *Proceedings of the ASA's 37th national conference on autism spectrum disorders*.
- Bristol, M. M., & Schopler, E. (1984). A development perspective on stress and coping in families of autistic children. In *Severely handicapped children and their families* (pp. 91–141). New York: Academic Press.
- Britner, P., Morog, M., Pianta, R., & Marvin, R. (2003). Stress and coping: A comparison of self-report measures of functioning in families of young children with cerebral palsy or no medical diagnosis. *Journal of Child & Family Studies, 12*(3), 335.
- Brobst, J., Clopton, J., & Hendrick, S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism & Other Developmental Disabilities, 24*(1), 38-49.
- Bromley, J., Hare, D., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders. *Autism: The International Journal of Research & Practice, 8*(4), 409-423.
- Burden, R. (1991, December). Psycho-social transitions in the lives of parents of children with handicapping conditions. *Counseling Psychology Quarterly, 4*(4), 331.
- Centers for Disease Control, Developmental Disabilities (CDC). Retrieved March 4, 2009, From *Prevalence of the Autism Spectrum Disorders in Multiple Areas of the United States, Surveillance Years 2000 and 2002* Web site:  
<http://www.cdc.gov/ncbddd/dd/addmprevalence.htm>

- Chesler, M. A., & Parry, C. (2001). Gender roles and/or styles in crisis: An integrative analysis of the experiences of fathers of children with cancer. *Qualitative Health Research, 11*(3), 363-384.
- Cho, S., Singer, G., & Brenner, M. (2000). Adaptation and accommodation to young children with disabilities: A comparison of Korean and Korean American parents. *Topics in Early Childhood Special Education, 20*(4), 236.
- Creswell, J. (2007). *Qualitative inquiry & research design*. Thousand Oaks: CA. Sage Publications, Inc.
- Crnic, K.A., Friedrich, W.N., & Greenberg, M.T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping and family ecology. *American Journal of Mental Deficiency, 88*, 125-136.
- Davis, N., & Carter, A. (2008, August). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: associations with child characteristics. *Journal of Autism & Developmental Disorders, 38*(7), 1278-1291.
- Dollahite, D., Marks, L., & Olson, M. (1997, November 1). Faithful fathering in trying times: Religious beliefs and practices of Latter-Day Saint fathers of children with special needs. (ERIC Document Reproduction Service No. ED416034).
- Drotar, D., Baskiewicz, A., Irvin, N., Kennell, J., & Klaus, M. (1975). The adaptation of parents to the birth of an infant with a congenital malformation: A hypothetical model. *Pediatrics, 56*(5), 710.
- Dumas, J.E., Wolf, L.C., Fisman, S.N., & Culligan, A. (1991). Parenting stress, child behavior problems and dysphoria in parents of children with autism, down syndrome, behavior disorders, and normal development. *Exceptionality, 2*(2), 97-110.

- Dunlap, G., & Bunton-Pierce, M. (1999). Autism and Autism Spectrum Disorders (Report No. ED436068). Reston, VA: ERIC Clearing House on Disabilities and Gifted Education.
- Dyson, L. (1991). Families of young children with handicaps: parental stress and family functioning. *American Journal on Mental Retardation*, 95(6), 623-629.
- Dyson, L. (1993). Response to the presence of a child with disabilities: parental stress and family functioning over time. *American Journal on Mental Retardation*, 98(2), 207-218.
- Dyson, L. (1997). Fathers and mothers of school-age children with developmental disabilities: parental stress, family functioning, and social support. *American Journal on Mental Retardation*, 102(3), 267-279.
- Dyson, L., & Fewell, R. (1986). Stress and adaptation in parents of young handicapped and non-handicapped children: A comparative study. *Council of Exceptional Children Division for Childhood Journal*, 10(1), 25-35.
- Ellis, J. (1989). Grieving for the loss of the perfect child: Parents of children with handicaps. *Child & Adolescent Social Work Journal*, 6(4), 259-270.
- Esdale, S., & Greenwood, K. (2003). A comparison of mother's and father's experience of parenting stress and attributions for parent-child interaction outcomes. *Occupational Therapy International*, 10(2), 115-126.
- Featherstone, H. (1980). *A Difference in the Family: Life with a Disabled Child*. New York: Basic Books.

- Ferguson, P. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *Journal of Special Education*, 36(3), 124.
- Fisman, S. N., Wolf, L. C., & Noh, S. (1989). Marital intimacy in parents of exceptional children. *Canadian Journal of Psychiatry*, 34, 519-525.
- Floyd, K., & Morman, M. T. (2003). Human affection exchange II: Affectionate communication in father-son relationships. *The Journal of Social Psychology*, 143(5), 599-612.
- Fombonne, E. (1999). The epidemiology of autism: A review. *Psychological Medicine*, 29(4), 769-786.
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disabilities: An update. *Journal of Autism and Developmental Disorders*, 33, 365-382.
- Fombonne, E. (2005a). The changing epidemiology of autism. *Journal of Applied Research in Intellectual Disabilities*, 18, 281-294.
- Fombonne, E. (2005b). Epidemiological studies of pervasive developmental disorders. In *Handbook of autism and pervasive developmental disorders: Vol. 1. Diagnosis, development, neurobiology, and behavior* (3rd ed., pp. 165-200) Hoboken, NJ: John Wiley and Sons, Inc.
- Frith, U. (2003). *Autism: Explaining the enigma* (2nd ed.) Malden, MA: Blackwell.
- Gammon, E., & Rose, S. (1991). The coping skills training program for parents of children with developmental disabilities: An experimental evaluation. *Research on Social Work Practice*, 1(3), 244-256.

- Glaze, D. G. (2005). Neurophysiology of Rett syndrome. *Journal of Child Neurology*, 20, 740-746.
- Glesne, C. (1999). *Becoming Qualitative Researchers: An Introduction* (2nd). University of Vermont: Longman.
- Glidden, L., & Bush, B. (1990, May 1). *Adoptive and Birth Family Adjustment to Rearing Retarded Children*. (ERIC Document Reproduction Service No. ED323735).
- Gold, N. (1990). A gender analysis of families of autistic boys: Social adjustment and depression. *Dissertation Abstracts International*, 344.
- Gray, D.E. (1994). Coping with autism: Stresses and strategies. *Sociology of Health and Illness*, 16(3), 275-300.
- Gray, D. (2002). Ten years on: a longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability*, 27(3), 215-222.
- Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science and Medicine*, 56, 631-642.
- Gray, D. E. (2006). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, 50(12), 970-976.
- Happé, F. (1995). *Autism: An introduction to psychological theory*. Cambridge, MA: Harvard University Press.
- Harris, S. (2008, January 25). *Autism society of America: Sibling issues*. Retrieved from [http://www.autism-society.org/site/PageServer?pagename=life\\_fam\\_sibling](http://www.autism-society.org/site/PageServer?pagename=life_fam_sibling)
- Hastings, R. P. (2003). Child behavior problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research*, 47(4/5), 231-237.

- Hastings, R., Kovshoff, H., Ward, N., Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism & Developmental Disorders*, 35(5), 635-644.
- Haworth, A., & Hill, A. (1996). Measuring religiousness of parents of children with developmental disabilities. *Mental Retardation*, 34(5), 271-279.
- Herring, S., Gray, K., Taffe, J., Tonge, B., Sweeney, D., & Einfeld, S. (2006). Behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. *Journal of Intellectual Disability Research*, 50(12), 874-882.
- Housey, A., Best, S., & Blacher, J. (1992). Mothers' and fathers' perceptions of stress and coping with children who have severe disabilities. *American Journal on Mental Retardation*, 97(1), 99-110.
- Huber, C. H. (1979). Parents of the handicapped child: Facilitating acceptance through group counseling. *Personnel and Guidance Journal*, 57, (5), 267-269.
- Individuals with Disabilities Education Improvement Act of 2004.(2004). Individuals with Disabilities Education Act (IDEA), 20 U.S.C. § 1400. Available at: [http://www.congress.gov/cgi-bin/cpquery/R?cp108:FLD010:@1\(hr779\)](http://www.congress.gov/cgi-bin/cpquery/R?cp108:FLD010:@1(hr779)).
- Kanner, L., & Eisenberg, L. (1956). Early infantile autism 1943-1955. *American Journal of Orthopsychiatry*, 26, 556-566.
- Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of Autism & Developmental Disorders*, 27(1), 39-57.

- Keller, D., & Honig, A. (2004). Maternal and paternal stress in families with school-aged children with disabilities. *American Journal of Orthopsychiatry*, 74(3), 337-348.
- Kerr, S., & McIntosh, J. (2000). Coping when a child has a disability: exploring the impact of parent-to-parent support. *Child: Care, Health & Development*, 26(4), 309-322.
- Kirkham, M., Schilling, R., Norelius, K., & Schinke, S. (1986). Developing coping styles and social support networks: An intervention outcome study with mothers of handicapped children. *Child: Care, Health and Development*, 12(5), 313-323.
- Klin, A., McPartland, J., & Volkmar, F. R. (2005) Asperger syndrome. In *Handbook of autism and pervasive developmental disorders: Vol. 1. Diagnosis, development, neurobiology, and behavior* (3rd ed., pp. 5-41) Hoboken, NJ: John Wiley and Sons, Inc.
- Konstantareas, M. M., & Homatidis, S. (1992). Mothers' and fathers' self report of involvement with autistic, mentally delayed, and normal children. *Journal of Marriage and the Family*, 54(1), 153-164.
- Kozinetz, C. A., Skender, M. L., MacNaughton, N., Almes, M. J. , Schultz, R. J., Percy, A. K., & Glaze, D. G. (1993). Epidemiology of Rett syndrome: A population-based registry. *Pediatrics*, 91, 445-450.
- Krauss, M. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation*, 97(4), 393-404.
- Kubler-Ross, E. (1969). *On Death and Dying*. London: Routledge.

- Kwai-sang Yau, M., & Cecilia W. P., L. (1999). Adjustment and adaptation in parents of children with developmental disability in two-parent families: A review of the characteristics and attributes. *British Journal of Developmental Disabilities*, 45(88), 38-51.
- Lamb, M. E. ,& Tamis-Lamonda, C. S. (2004). The role of the father: an introduction. In M. E. Lamb (Ed.), *The Role of the Father in Child Development* (pp. 1-31). Hoboken, N.J.: John Wiley & Sons, Inc.
- Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50(3), 172-183.
- Lee, L., Harrington, R., Louie, B., & Newschaffer, C. (2008, July). Children with autism: Quality of life and parental concerns. *Journal of Autism & Developmental Disorders*, 38(6), 1147-1160.
- Leyser, Y., Heinze, A., & Kapperman, G. (1996). Stress and adaptation in families of children with visual disabilities. *Families in Society*, 77(4), 240-249.
- Lingam, R., Simmons, A., Andrews, N., Miller, E., Stowe, J., & Taylor, B. (2003). Prevalence of autism and parentally reported triggers in a north east London population. *Archives of Disease in Childhood*, 88, 666-670.
- Long, A. L. (2005). Understanding fathers' experiences of raising an autistic son: A qualitative study. ProQuest Information and Learning Company, Ann Arbor, MI. (UMI No. 3160177)
- Longenecker, H. Q. (2002). Parent stress related to having a child with autism: Impact of educational programming. *Fielding Graduate Institute*. UMI. (UMI No. 3077548)

- Louie, E. (1996, May 30). Currents: A new web site for coping parents. *New York Times*, Retrieved April 17, 2009, from Academic Search Premier database.
- Luther, E., Canham, D., & Cureton, V. (2005). Coping and social support for parents of children with autism. *Journal of School Nursing, 21*(1), 40-47.
- Malhotra, S., & Gupta, N. (1999). Childhood disintegrative disorder. *Journal of Autism and Developmental Disorders, 29*, 491-498.
- Marcus, L. M., Kunce, L. J., & Schopler, E. (2005). Working with families. In *Handbook of autism and pervasive developmental disorders: Vol. 2. Assessment, interventions, and policy* (3rd ed., pp. 1055-1086) Hoboken, NJ: John Wiley and Sons, Inc.
- Marvin, R. S., & Pianta, R. C. (1996). Mothers' reactions to their child's diagnosis: Relations with security of attachment. *Journal of Clinical Child Psychology, 25*(4), 436-445.
- McCarthy, A., Cuskelly, M., van Kraayenoord, C., & Cohen, J. (2006). Predictors of stress in mothers and fathers of children with Fragile X Syndrome. *Research in Developmental Disabilities, 27*(6), 688-704.
- Merriam, S.B. (1998). *Qualitative Research and Case Study Applications in Education* (p. 275). San Francisco: Jossey-Bass.
- Morison, J., Bromfield, L., & Cameron, H. (2003). A therapeutic model for supporting families of children with a chronic illness or disability. *Child & Adolescent Mental Health, 8*(3), 125-130.
- Morbidity and Mortality Weekly Report*. (2002). Prevalence of autism spectrum disorders - Autism and developmental disabilities monitoring network, 14 sites, United States, 2002. Centers for Disease Control and Prevention.

- Morman, M. T., & Floyd, K. (2002). A "changing culture of fatherhood": Effects on affectionate communication, closeness, and satisfaction in men's relationships with their fathers and their sons. *Western Journal of Communication*, 66(4), 395-411.
- Mouridsen, S. E. (2003). Childhood disintegrative disorder. *Brain & Development*, 25, 225-228.
- Muhle, R., Trentacoste, S.V., & Rapin, I. (2004). The genetics of autism. *Pediatrics*, 113(5), 472-486.
- National Institute of Mental Health, (2008). *Autism spectrum disorders: Pervasive developmental disorders*. Bethesda, MD: NIMH.
- Neely-Barnes, S., & Dia, D. (2008). Families of children with disabilities: A review of literature and recommendations for interventions. *Journal of Early & Intensive Behavior Intervention*, 5(3), 93-107.
- Noh, S., Dumas, J.E., Wolf, L.C., & Fisman, S.N. (1989). Delineating sources of stress in parents of exceptional children. *Family Relations*, 38(4), 456-461.
- Nolan, K., Camfield, C., & Camfield, P. (2008). Coping with a child with Dravet Syndrome: Insights from families. *Journal of Child Neurology*, 23(6), 690-694.
- Nord, C. W. (1998). Dads' involvement in their kids' schools. *Education Digest*, 63(7), 29-35.
- Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual & Developmental Disability*, 31(1), 1-12.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 43, 190-193.

- Pain, H. (1999). Coping with a child with disabilities from the parents' perspective: The function of information. *Child: Care, Health & Development*, 25(4), 299-313.
- Patton, M. (2002). *Qualitative Research and Evaluation Methods* (3rd ed., p. 589). Thousand Oaks, California: Sage Publications.
- Pitchlyn, C., Smith-Myles, B., & Cook, V. (2007). Urban parents' perceptions about the role of organized religion and spiritual beliefs in their family life. *Multiple Voices for Ethnically Diverse Exceptional Learners*, 10(1/2), 8-16.
- Pinborough-Zimmerman, J., Satterfield, R., Miller, J., Bilder, D., Hossain, S., & McMahon, W. (2007, November). Communication disorders: Prevalence and comorbid intellectual disability, autism, and emotional/behavioral disorders. *American Journal of Speech-Language Pathology*, 16(4), 359-367. Retrieved March 21, 2009, doi:10.1044/1058-0360(2007/ 039)
- QSR International. (2006). NVivo 7.
- Rasmussen, F. R. (2000). *Parental reaction to having a child diagnosed with autism*. Unpublished, M.S.thesis, Miami University, Dept. of Family Studies and Social Work. Oxford, Ohio.
- Reid, S. (1999). The Assessment of the child with autism: a family perspective. *Clinical Child Psychology and Psychiatry*, 4(1), 63-78.
- Saloviita, T., Itälina, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A double ABCX model. *Journal of Intellectual Disability Research*, 47(4/5), 300-312.
- Schieve, L., Blumberg, S., Rice, C., Visser, S., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics*, 119, S114-S121.

- Schilling, R., Gilchrist, L., & Schinke, S. (1984). Coping and social support in families of developmentally disabled children. *Family Relations*, 33(1), 47.
- Schneider, J. (1983). *The nature of loss, the nature of grief: A comprehensive model for facilitation and understanding*. Baltimore: University Park Press.
- Schnur, J. (2005). Asperger syndrome in children. *Clinical Practice*, 17, 302-308.
- Schwartzman, M.A. (1983). Father and atypical son: A study of social interaction. *Dissertation Abstracts International*, 178.
- Shechtman, Z., & Gilat, I. (2005). The effectiveness of counseling groups in reducing stress of parents of children with learning disabilities. *Group Dynamics: Theory, Research, and Practice*, 9(4), 275-286.
- Shin, J., Nhan, N., Crittenden, K., Hong, H., Flory, M., & Ladinsky, J. (2006). Parenting stress of mothers and fathers of young children with cognitive delays in Vietnam. *Journal of Intellectual Disability Research*, 50(10), 748-760.
- Shonkoff, J., & Others, A. (1992, January 1). Development of Infants with Disabilities and Their Families: Implications for Theory and Service Delivery. *Monographs of the Society for Research in Child Development*, 57(6), 1-153.
- Singer, G., & Others, A. (1989). Evaluation of community-based support services for families of persons with developmental disabilities. *Journal of the Association for Persons with Severe Handicaps (JASH)*, 14(4), 312-23.
- Solnit, A., & Stark, M. (1961). Mourning and the birth of a defective child. *Psychoanalytic Study of the Child*, 16, 523-537.

- Solomon, M., Pistrang, N., & Barker, C. (2001). The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology*, 29(1), 113.
- Szatmari, P., & Archer, L. (1994). Parent and teacher agreement in the assessment of pervasive developmental disorders. *Journal of Autism & Developmental Disorders*, 24(6), 703-717.
- Taanila, A., Syrjälä, L., Kokkonen, J., & Järvelin, M. (2002). Coping of parents with physically and/or intellectually disabled children. *Child: Care, Health & Development*, 28(1), 73-86.
- Tarakeshwar, N., & Pargament, K. (2001). Religious coping in families of children with autism. *Focus on Autism & Other Developmental Disabilities*, 16(4), 247.
- Towbin, K. E. (2005). Pervasive developmental disorder not otherwise specified. In *Handbook of autism and pervasive developmental disorders: Vol. 1. Diagnosis, development, neurobiology, and behavior* (3rd ed., pp. 165-200) Hoboken, NJ: John Wiley and Sons, Inc.
- Tucker, P. (2005, September-October). Stay at home dads: At-home dads can benefit children and mothers. *The Futurist*, 12-13.
- Turbiville, V.P., & Marquis, J.G. (2001). Father participation in early education programs. *Topics in Early Childhood Special Education*, 21(4), 223-231.
- U. S. Department of Education. (2002). *Digest of education statistics*. Washington, D. C.: Author

- Van Acker, R. V., Loncola, J. A., & Van Acker, E. Y. (2005). Rett syndrome: A pervasive developmental disorder. In *Handbook of autism and pervasive developmental disorders: Vol. 1. Diagnosis, development, neurobiology, and behavior* (3rd ed., pp. 5-41) Hoboken, NJ: John Wiley and Sons, Inc.
- Volkmar, F. R., & Klin, A. (2005). Issues in the classification of autism and related conditions. In *Handbook of autism and pervasive developmental disorders: Vol. 1. Diagnosis, development, neurobiology, and behavior* (3rd ed., pp. 5-41) Hoboken, NJ: John Wiley and Sons, Inc.
- Volkmar, F. R., Koenig, K., & State, M. (2005). Childhood disintegrative disorder. In *Handbook of autism and pervasive developmental disorders: Vol. 1. Diagnosis, development, neurobiology, and behavior* (3rd ed., pp. 70-87) Hoboken, NJ: John Wiley and Sons, Inc.
- Volkmar, F.R., Lord, C., Bailey, A., Schultz, R.T., & Klin, A. (2004). Autism and pervasive developmental disorders. *Journal of Child Psychology and Psychiatry*, 45(1), 135-170.
- Waltz, M. (2002). *Autistic spectrum disorders: Understanding the diagnosis and getting help* (2nd ed.) Sebastopol, CA: O'Reilly & Associates, Inc.
- Weisner, T., & Others, A. (1991). Religion and families of children with developmental delays. *American Journal on Mental Retardation*, 95(6), 647-62.
- Whelan, T. B., & Walker, M. L. (2009). Coping and adjustment of children with neurological disorder. In *Handbook of clinical child neuropsychology* (3rd ed., pp. 703-728) Springer-Verlag, NY: Springer.

- Williams, C., & Wright, B. (2004). *How to Live with Autism and Asperger Syndrome: Practical Strategies for Parents and Professionals*. London: Jessica Kingsley.
- Retrieved September 7, 2008, from Questia database:  
<http://www.questia.com/PM.qst?a=o&d=113774778>
- Wilton, K., & Renaut, J. (1986). Stress levels in families with intellectually handicapped preschool children and families with non-handicapped preschool children. *Journal of Mental Deficiency Research*, 30(2), 163-169.
- Wing, L. (1988). The continuum of autistic characteristics. In E. Schopler & G. B. Mesibov (Eds.), *Diagnosis and Assessment in Autism* (pp. 91-110). New York: Plenum Press.
- Wing, L. (1997). Syndromes of autism and atypical development. In D. J. Cohen & F. R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (2nd ed., pp. 148-170) New York: John Wiley & Sons, Inc.
- Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9, 11-29.
- Witwer, A. N., & Lecavalier, L. (2008). Examining the validity of autism spectrum disorder subtypes. *Journal of Autism and Developmental Disorders*, 38, 1611-1624.
- World Health Organization. *The ICD-10 Classification of Mental and Behavioural Disorders*. Retrieved March 5, 2005, from  
<http://www.who.int/classifications/icd/en/bluebook.pdf>
- Yablonsky, L. (2000). *Fathers and Sons: Life Stages in One of the Most Challenging of All Family Relationships*. Lincoln, Nebraska: Excel Press.

Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C.

(2003). Prevalence of autism in a US metropolitan area. *Journal of the American Medical Association*, 289(1), 49–55.

Yell, M. L., & Katsiyannis, A. (2003). Critical issues and trends in the education of students with autism spectrum disorders: Introduction to the special edition. *Focus on Autism and Other Developmental Disabilities*. 18, 138-139.

Zaidman-Zait, A., & Jamieson, J. (2007). Providing web-based support for families of infants and young children with established disabilities. *Infants & Young Children: An Interdisciplinary Journal of Special Care Practices*, 20(1), 11-25.

Ziolko, M. E. (1991). Counseling parents of children with disabilities: A review of the literature and implications for practice. *The Journal of Rehabilitation*, 57(2), 29.

## APPENDIX A

### Letter of Informed Consent

I agree to be interviewed by Jeff Isenhour, a doctoral candidate in Educational Leadership at Appalachian State University, in Boone, North Carolina. The purpose of these interviews is to provide information for the completion of dissertation research on the experiences of fathers of sons with autism spectrum disorders and their perceptions related to fathering a son with autism. This research is being completed under the supervision of a dissertation committee and chair, Dr. David Koppenhaver.

As a participant in this research, I understand that I will be asked about my experiences as a father of a son with autism and my views related to fatherhood. Interviews will consist of three different meetings. The first interview will involve answering initial interview questions related to my son's diagnosis, views on fatherhood, and experiences as a result of being the father of a son with an autism spectrum disorder. The second interview will involve answering any follow-up questions from the first interview and clarifying any responses from the first interview. The third interview will involve a review of interview transcripts to clarify any responses from the first two interviews and check for response accuracy. All interviews will be tape recorded for later transcription and analysis. I understand that the information from these interviews, combined with that of other participants, will become part of a doctoral dissertation study, which will be written and published.

I understand that my confidentiality and my son's confidentiality will be protected. Our names and identities will be protected by using pseudonyms with all identifying information removed from transcripts. At the completion of all research transcription, all tape recordings will be erased. All materials related to this research will be secured in a locked cabinet.

I understand that there are no foreseeable risks associated with taking part in this study. However, I understand that interviews questions may bring up areas of discussion that may cause mild discomfort as I describe my experiences related to my son with an autism spectrum disorder. If I do experience discomfort, I may stop the interview at any time.

I understand that my participation in these interviews is voluntary and that I may choose to stop participating at any time. If I refuse to participate, there will be no repercussions. I understand that if I have questions or concerns regarding my rights as a participant I can contact Robert L. Johnson, Administrator, Institutional Review Board, Graduate Studies and Research, Appalachian State University, at (828) 262-2692.

#### Consent Statement

I have read and understand the information above. The researcher has answered all of the questions I had to my satisfaction. I was given a copy of this form. I consent to take part in this dissertation study on the experiences of fathers of sons with an autism spectrum disorder and their perceptions related to fathering a son with an autism spectrum disorder.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## APPENDIX B

Jeff Isenhour  
101 3<sup>rd</sup> Street, SE  
Catawba, NC 28609

Dear Parent:

My name is Jeff Isenhour. Currently, I am completing my doctoral degree in Educational Leadership at Appalachian State University, in Boone, North Carolina. In order to complete my degree, I must complete a doctoral research study for my dissertation. My research is focused on the experiences of fathers of sons with an autism spectrum disorder and their perceptions related to fathering a son with an autism spectrum disorder. This research is being completed under the supervision of a dissertation committee and chair, Dr. David Koppenhaver.

In order to complete this research, I need to interview fathers of boys with an autism spectrum disorder. I feel there is a great need to understand the experiences that parents, especially fathers, experience in raising a child with an autism spectrum disorder.

Participants in this research will be asked about their experiences as a father of a son with an autism spectrum disorder and their views related to fatherhood. Interviews will consist of three different meetings. The first interview will involve answering initial interview questions related to diagnosis, views on fatherhood, and experiences as a result of being the father of a son with autism an autism spectrum disorder. The second interview will involve answering any follow-up questions from the first interview and clarifying any responses from the first interview. The third interview will involve a review of interview

transcripts to clarify any responses from the first two interviews and check for response accuracy. The completed dissertation will be written and published.

Fathers participating in this project will be protected under confidentiality guidelines held by Appalachian State University. If you are interested in participating in this study, please contact me. I hope you will consider participating and adding to this area of knowledge. I look forward to hearing from you.

Respectfully,

Jeff Isenhour

Home Phone – 828-241-9623

Mobile – 828-308-5844

Email – Jeffrey\_Isenhour@catawba.k12.nc.us

## APPENDIX C

### Interview Questions

#### Diagnosis

1. Tell me about your son.
2. How and when did you first learn that your son had autism?
3. Can you describe your reaction(s) when you learned that your son had autism?
4. In what ways is your son like other boys who don't have autism? In what ways is he different?
5. Do you have concerns or worries as a father of a son with autism? What are they? Do you think they are different from other fathers? How are they different?
6. How are your concerns or worries different or similar to your wife (or son's mother)?

#### Fatherhood

1. Can you tell me about your own childhood and your experiences with your father?
2. How did your own experiences with your father affect your experiences with your son?
3. What has been most gratifying and most difficult for you as a father in having a son with autism?
4. What are your responsibilities as a father with a son with autism?
5. How are your responsibilities different from your wife (or the mother of your son)?
6. How are you involved with your son's education?
7. How do you feel when you are around other fathers?

8. Do you have relationships with fathers of children with autism or special needs?

Describe those relationships.

9. Has your son changed your family social life? How?
10. What are your hopes and dreams for your son's future?

#### Changing Experiences

1. What resources have you used to help your son?
2. Has your view on being a father changed? How?
3. Has the experience of having a son with autism changed your views on being a father? How?
4. Do you have other children? Are they older or younger?
5. Has your experience of having a son with autism affected your decision to have other children? How?
6. Do you parent all of your children the same or differently? Can you explain?
7. Does having a son with autism affect your relationship with your other children? How?
8. What are the most important things you would share with others about your experiences of being a father of a son with autism?
9. Would you like a copy of tapes, transcripts, the final report, or all three?

## APPENDIX D

## Guiding Interview Questions From Long (2005)

1. Can you tell me the first time you heard your son's diagnosis?
2. What were you the most concerned or worried about?
3. Are there different worries that you and your child's mother have?
4. What is it like for you when you talk to fathers of typically developing children?
5. What is it like for you when you talk to fathers of developmentally delayed children?
6. How has the experience of having your son changed your family?
7. In what ways would you like to be more involved in your son's education?
8. How has your son impacted you and your family socially?
9. What advice would you give to other fathers who are just learning about their son's diagnosis

## APPENDIX E

## Field Memo – Tim

October 1, 2007

I just finished my first interview with Tim at Dos Amigos in Hickory. Tim and I met for about two hours at lunch. Tim was running late to the meeting and called me on his cell phone. He had been at a school meeting with his son Matthew. Tim is a fascinating guy. He seems he is a wonderful father. Things I thought of from my meeting with Tim dealt with grandparents and grandfathers and how they fit into the whole picture. I guess I wouldn't have thought about in-laws and their perceptions but he sparked that in my mind today. This may be something I want to follow up on if it shows up in other interviews.

This was a great experience as an interview. Tim also shared that he thought this was great. He also shared that he thought he could talk about this all day. This was good for me to hear. I was worried about fathers coming in and not being able to open up and talk about their situations. The other thing that stood out was the fact that Tim admitted that these fathers are hard to find and get in the door. He also mentioned the 80% divorce rate in families and the fact that in the support group, there are only about 4 or 5 dads that he sees out of these 11 to 13 families. I do need to add that piece into the research about families and the dysfunctionality they have and the high rate of divorce. He mentioned that this was like therapy. I need to choose restaurants where the music is not too loud.

I think we can begin to establish some validity from the interview with Tim, with him mentioning that this was a worthwhile thing to do for fathers. He said that he had talked to

me more about his son with autism than he had with anybody else. I also think it bears to mention that when these guys go to support groups, they are not talking about fatherhood. It also matters that over the chips, Mexican food, etc., I think this was a good way of building rapport with these parents than in a quiet, sterile situation. You could hear better, but it may not be the better place.

Tim also shared that there was one other guy in the group that he thought would participate. He will contact him this week and let me know if he is willing to do this. Tim works at \_\_\_\_\_ in the research area. His wife's name is Faith. He is from the Washington, DC area and has been down here for a good while. He has two boys. One seven and one five. Tim did not tell me his age. I need to ask this.

One piece that came to the forefront with me was the religious piece. If I remember, there was some research done about Mormons and special education. I do not remember if that dealt with children with autism or what. Tim also said several times that lunch time was the best time for him to meet. I think I need to look at when these guys can actually get away. He mentioned that in the evenings, he has to be at home with his family. The participation piece with being breadwinner and supporting the family has to be looked at and considered here.

## APPENDIX F

## Field Memo – Edward

October 5, 2007

I just finished my first interview with Edward. We met at Fatz at 12:30 and got us a booth. We ordered some hot wings. Edward is a big guy. He has three boys. Tommy is the oldest of seven, Nathan is five, and a son that is two. Nathan is the son that has classic autism. We talked about Tommy and Nathan the most.

I thought it was interesting to hear Edward talk about his own father and what kind of a man he was and the relationship that he has with him and the relationship with his brothers. He mentioned that this is an emotional issue with him. He worries about his son's future. He also talked about the joy he had when Nathan first started to speak.

One of the things I want to follow up with these guys is the support group piece. I am not sure that I have really heard them talk about what they are getting out of this as fathers or as men. Edward basically said that it was not his thing. The second item is the piece about grandfathers and how they view their grandsons with autism. There is also the piece about social issues and going out in public. There is the frustration of weekly issues.

I promised Edward that I would call him back on Monday. At the end of the interview, Edward wanted to know my opinions about what is the cause of this. He mentioned that as a father, you really do a lot of self-analysis. I also want to go back and ask questions about the emotions you experience. With the family structure behind you, is this

easier to deal with if you have that type of support structure? He did mention the being raised in a Christian home but did not elaborate on if that is a support structure today.

## APPENDIX G

## Letter for Consent to Conduct Dissertation Research

101 3rd Street SE  
Catawba, NC 28609  
November 5, 2006

Dr. Paul Holden  
PO Box 1010  
10 East 25th Street  
Newton, NC 28568  
Attention: Research Review Committee  
Subject: Request for consent to conduct dissertation research

Dear Dr. Holden:

As part of my requirement for the completion of my doctoral degree from Appalachian State University, I am in the process of completing my dissertation research. My research involves a phenomenological study focusing on the experiences and perceptions of fathers of sons with autism. In order to complete this study, I will interview fathers of boys with autism.

I am writing to formally request permission to contact the appropriate school personnel in Catawba County Schools in order that they may provide information regarding my research to fathers of boys with autism as well as to acquire contact information of possible participants. Specific contact of school personnel will include the Director of Exceptional Children, any teachers supervising classrooms with children with autism, and the administrative personnel within the school system at schools that contain classes with children with autism.

Any activities related to my research will not pose any interruption to the school or district program nor make any undue demands on the time of teachers or administrators. In addition, all requirements of this research are subject to approval by the Institutional Review Board of Appalachian State University. I am including a copy of the research prospectus for your review and a consent form for participants. I look forward to hearing from you in the near future regarding this request.

Respectfully,

Jeff Isenhour  
Appalachian State University

## APPENDIX H

Office Use Only

## APPALACHIAN STATE UNIVERSITY

## REQUEST FOR REVIEW OF HUMAN PARTICIPANTS RESEARCH

Please type and submit one copy to the Chairperson, IRB, c/o Graduate Studies and Research, John E. Thomas Building.

1. Date: 8/10/07
2. Project Title: Changing Perceptions of Fatherhood Among Fathers With Sons Who Have Autism
3. Principal Investigators: Jeff Isenhour
4. Phone: 828-241-9623      5. E-mail address: Jeffrey\_Isenhour@catawba.k12.nc.us
6. Academic Department/Unit: Education / Educational Leadership
7. Relationship to Appalachian State University (T): Faculty \_\_\_\_\_ Staff \_\_\_\_\_  
Graduate Student X Undergraduate Student \_\_\_\_\_
8. If student, name of faculty mentor: Dr. David Koppenhaver
9. Faculty mentor's e-mail address: koppenhaverd@appstate.edu
10. This is (T): specific project X grant proposal \_\_\_\_\_ other \_\_\_\_\_
11. Funding agency/sponsor (if applicable): \_\_\_\_\_
12. Projected data collection dates: 8/25/07 to 11/15/07
13. Have the investigators completed training in the use of humans in research?  
Yes X No \_\_\_\_\_

I have read Appalachian State University's Policy and Procedures on Human Subjects Research and agree to abide them. I also agree to report and significant and relevant changes in procedures and instruments as they relate to participants to the Chairperson of the Institutional Review Board

<u>David Koppenhaver</u> PI	<u>8-13-07</u> Date	_____	_____
<u>David Koppenhaver</u> If PI is student, Faculty Mentor	<u>8/13/07</u> Date	_____	_____
<u>DPK</u>		Co-investigator	Date
		Co-investigator	Date

## BIOGRAPHICAL SKETCH

Jeff Isenhour was born in Hickory, North Carolina on June 1, 1969. He graduated from Newton-Conover High School in Catawba County, North Carolina in 1987. Mr. Isenhour completed his Doctorate in Educational Leadership from Appalachian State University in 2010. He has an Educational Specialist Degree in Educational Leadership from Appalachian State University, a Master's in School Administration from Gardner-Webb University, a Master's in Political Science from Appalachian State University, North Carolina teaching license from Lenoir-Rhyne University, and a Bachelor's Degree in Political Science from Appalachian State University.

Mr. Isenhour began his career in education as a middle school teacher. He has been an elementary school assistant principal, elementary principal, and middle school principal. Mr. Isenhour enjoys traveling. He has traveled to China and Finland to visit schools in order to understand the educational systems of these countries. Mr. Isenhour has previously served on the advisory board for World View, an international program for educators, located at the University of North Carolina at Chapel Hill. In addition, he is a member of Phi Delta Kappa (PDK), the Association of Supervision and Curriculum Development (ASCD), the National Association of Elementary School Principals (NAESP), the National Middle School Association (NMSA), and the National Association of Secondary School Principals (NASSP).

Mr. Isenhour has completed the Principals as Technology Leaders (PATL) program and the Leadership Program for Experienced Principals (LPXP) at the Principal's Executive Program at the University of North Carolina at Chapel Hill. In addition, Mr. Isenhour has completed the

Global Education Leaders Program sponsored by World View at the University of North Carolina at Chapel Hill.

Mr. Isenhour believes in the value of civic and community service. He has served as the vice-chair of the Town of Catawba Planning and Zoning Board and the Charter President of the former Catawba Civitan Club. Mr. Isenhour serves as an elected official on the Town Council in the Town of Catawba and as a former member of the Newton-Area Council as part of the Catawba County Chamber of Commerce. He is a proud member of the Catawba Valley Rotary Club. Mr. Isenhour is married to Jo-Nell Isenhour. He and his wife have a son, John Paul. Mr. Isenhour enjoys gardening, reading, and spending time outdoors. He is an avid outdoorsman and enjoys playing golf. His home address is 101 3<sup>rd</sup> St. SE, Catawba, North Carolina.